



EVOLUTION OF DEVELOPMENTAL PAEDIATRICS IN HONG KONG: AN OVERVIEW

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Developmental Paediatrics, an established paediatric subspecialty professionally, is designated to promote normal child development, to identify children with developmental needs, and to provide optimum environment for all children to attain their highest potentials. The subspecialty comprises of three major components: *Developmental Screening (Surveillance) in a Community*, *Comprehensive Developmental Assessment* and *Neuro-Rehabilitation*. The subspecialty evolved in Hong Kong over the past five decades and can be classified into the Incubation Stage and the Maturation Stage according to the chronological development of events.

Incubation Stage

Germination

This started when Dr. Flora Baber came to Hong Kong from Uganda (East Africa) in November 1962 and went to meet Professor C Elaine Field in her tiny office in Queen Mary Hospital. Professor Field had just arrived in Hong Kong 6 months earlier as first holder of the chair of Paediatrics in the University of Hong Kong. In view that there were no standards of growth and development for Chinese infants and pre-school children, the two pioneers were keen to promote a longitudinal study on growth and development of Hong Kong children. The problems then were funding, venue and resources. The Professor of Anatomy, Professor KSF Chang and his staff were engaged in anthropometric, cross-sectional studies of Chinese school children at the time except that younger children were not included.

Whilst working in the Medical Research Council's Infantile Malnutrition Research Unit in Kampala, Uganda from 1950-61, Dr. Flora Baber had been studying the development of African babies with Dr. Marcelle Geber, a French child psychiatrist, who found that African babies from rural homes, brought up in the traditional way (i.e. breast fed and personally nursed by their mothers), were significantly more advanced in their motor development, in comparison with babies in urban areas, from well-to-do families who were artificially fed and left in their cots between feeds. At the time the difference between the types of feeding was not appreciated. Her method of developmental assessment was that of Drs O Brunet and I Lezine. This same method was being contemporarily used by 8 different centers in Europe, Scandinavia and West Africa in collaborative studies of child development. Professor Field and Dr. Baber decided to use this method of assessment for Chinese babies as it had no cultural bias.

After much hard work in the following months on planning the study and submitting the plans to various sponsors, Professor Field was delighted by the generosity of the Nuffield Foundation of England who donated enough money for the first 3 years and, after which, the Social Welfare Lotteries' Fund of Hong Kong Government sponsored the subsequent 5 years. Terms of reference were to study the growth and development of Chinese children with particular reference to their social environment. To carry out this study, the Medical and Health Department generously provided accommodation on half a floor in the Jockey Club Polyclinic in Yaumatei, Kowloon, where the first "Child Development Centre" was established.

Budding

At this time there were no Child Developmental Assessment Clinics in Hong Kong, Dr. Baber recruited and trained a Chinese medical officer, Dr Wong Yuk Sau, and 4 nursing staff via meetings designated to discuss methods and procedure for assessing child growth and development of Hong Kong children. The aim was to recruit a random sample of all babies born in Kwong Wah and Queen Elizabeth Hospitals over a period of 6 weeks with the objectives to include a representative sample of the population of Hong Kong. Six months before the study commenced Dr. Baber recruited 50 newborn babies from the same hospitals to act as controls (prototype), and to try out the procedures on the babies and questionnaire on the mothers to ensure that both were acceptable.

The design of the main study was to have a cohort of "regular attenders" of at least 500 babies, examined as soon as possible after their births. 782 babies were recruited between the end of February and beginning of April 1967. From this cohort after 3 years, Dr. Baber selected 542 "regular attenders", who were seen approximately every month in their first year; every 3 months in their 2nd & 3rd years; every 6 months in their 4th & 5th years and annually thereafter for statistical analysis. This was efficiently carried out by two prominent consultant statisticians, the late Mr. WZ Billewicz and Professor AM Thomson in the MRC's Reproduction and Growth Unit, Newcastle-upon-Tyne in England.

Unfortunately the time scale corresponded with the onset of the cultural revolution in China. Repercussions were felt in Hong Kong, when at one point there was no public transport in Kowloon. Recognising the difficulties for many of the families in coming to the clinic, Dr. Baber and her Team offered them "Home Assessments"

(Outreach Service as what we call nowadays). A maximum of 260 of these were carried out approximately every 3 months for 5 years, when traffic congestion forced the Team to abandon these in favour of annual visits to the clinic for all the remaining children.

At the onset of the study in 1967 Hong Kong was severely overcrowded, mainly by refugees from China, in spite of the considerable fall in the birth rate promoted by the Family Planning Association. The majority of these families were living in cramped, overcrowded conditions in tenement buildings; old style resettlement "H" blocks; squatter huts and roof-top dwellings.

Growing

Naturally, one of the major objectives of the Child Development Study was to find out effect of these environmental conditions on the development of Hong Kong children and the following significant observations were made during the follow-up.

Initially, for the first 3 months, Dr. Baber found the young babies, were co-operative (before they recognized strangers!) and relatively well-nourished, particularly those who were breast fed. But as they grew older towards toddlerhood they became inhibited and uncooperative, particularly the girls. These children were seldom taken outside their dark, crowded and ill-ventilated homes except to go to market. (Television had not arrived yet!) The Team was alarmed at their loss of weight between 4-6 months which corresponded with a high incidence of infection and the weaning period, when many babies were offered a bowl of watery congee as a substitute for milk. Baber and Field published their first book "Growing Up in Hong Kong" to draw attention to this problem. The weight loss in these babies was compounded by a seasonal effect. It was most marked in the height of summer and there was an attempt to "catch up" in the cooler winter months.

The difficulty facing the Team, as the children grew older from 3-5 years and beyond, was to find appropriate developmental tests that were not culturally biased. In the end they chose the Wechsler Pre-School & Primary Scale of Intelligence as it has an equal number of Verbal & Performance Tests. The latter proved to be popular with the children. In their fourth & fifth years many of the children were still inhibited, particularly in answering verbal tests. For this reason the Team could only use the results for 6-year-old children.

As the terms of reference for the Survey Team were to study the effect of the social environment on the development of our children, the nurses asked the mothers about the child's health, new additions to the family, the care of the child, including sleeping arrangements, and discipline at home and school at each clinic visit. In the first few years, migration of families was the norm, when difficulties with neighbours living in such close proximity, sharing cooking, washing and toilet facilities created problems. By the fifth year, in 1972, many of the families had moved out of their ill-ventilated, cramped quarters to much improved self-contained flats in both private and public housing. The effect of these social changes, accompanied by a dramatic rise in the family income of all social groups was self-evident, not only in the more outgoing behaviour of the children, but in their "catch up" growth. By the time of their last visit to the Clinic, around their ninth birthday, there was evidence of a significant secular trend in their growth in all parameters, especially in the boys.

Implementation and Outcome

Dr. Baber recalled as many as possible on or around their 15th birthday and 228 children attended the follow-ups. Although the majority of parents of the original cohort had less than primary or no education, the aspirations of both girls and boys at 15 years was impressive. Encouraged by their parents & grandparents to do their best in studying at school, many of these children were ambitious to excel and improve their own and their families' fortunes. The physical growth of both sexes showed evidence of a significant secular trend.

Maturation Stage

Developmental Paediatrics in Hong Kong: The Early Days

At the beginning of this study, there was no evidence of any interest in developmental paediatrics in Hong Kong. As in so many other countries it is a "Cinderella" specialty, lacking the drama and challenge of acute clinical & surgical paediatrics, it was considered to be dull & unattractive. But in the early years of the study, there was upheaval of interest internationally in developmental screening tests for young children and importance of early detection of abnormalities amenable to treatment.

It was the custom in the 1960's in Hong Kong, for families to keep children with obvious developmental defects confined to their homes away from the public eye, cared for by an elderly relative or in some cases abandoned altogether, as the staff of Po Leung Kuk children's home would testify. After a home visit, on one occasion the Team met a distressed mother who asked Dr. Baber to "test" her 5-year-old daughter, who had just been rejected by 3 schools; "Because she cannot speak properly", her mother said and added: "I know she is not stupid!" The child was later assessed and found to be highly intelligent with profound hearing impairment. Dr. Baber referred her to the school for the deaf, which was in its infancy stage. The child grew and developed well thereafter. Nowadays, it is totally unacceptable if a child's hearing loss should be missed by the age of five years old because there are good surveillance systems in the community to ensure early identification such as the newborn hearing screening tests, The Developmental Screening Test in the Community, the health education on Early Warning Signs for Hearing Impairment to parents and the public, and close vigilance of Pre-School & Primary school teachers who will recognize the problem and take appropriate action accordingly.

There were also speech problems in several children in the survey. Fortunately the Assessment Team had an excellent speech therapist sharing the same floor. Only one of 6 referred children attended for treatment more than once. The mothers failed to appreciate the importance of regular attendance for therapy to ensure optimum results to be achieved. When one child reached primary school age, her mother returned hoping for an "immediate cure" as the teacher had rejected the child as she "could not understand him".

Whilst the Team was preparing for the study, Professor Field was concerned with the lack of facilities for ongoing treatment for children with cerebral palsy of all grades. In the early days severely affected children were kept at home away from the public eye. Naturally their deformities grew worse as the authorities did not appreciate their mobility problems. Frequently the families had to accept a home higher than ground level where there were no lifts. As the children grew older their difficulties increased. They

received no physiotherapy. The result was spastic and functionless limbs. The Duchess of Kent Children's Hospital in Sandy Bay, Hong Kong Island, had very good physiotherapists in those days, but transport difficulties were formidable. The solution was a residential school for these children, as well as the training of more physiotherapists & occupational therapists in special day schools around the territory for which the Spastic Children's Association of Hong Kong was founded. The British National Spastics Association, (now called "SCOPE") gave a generous donation; enough to start a small school for 11 out of 30 children assessed, in premises kindly loaned by the Boys & Girls' Club. The chief publicity organizer, Mrs Li Fook Shu was able to stage a premiere film show of "Thomas a-Becket", which was attended by the Governor and elites of Hong Kong. It raised a substantial amount of money, as well as publicity for the work of the Association. Soon afterwards an American philanthropist visited Hong Kong looking for a suitable project to support. He gave enough funds for the residential school "the JF Kennedy Centre" to be built. Since then the Spastic Children's Association has been running special day schools around the territory. By then the public was more aware of the problems of such children and fewer of them were needlessly confined to their homes untreated.

Evolution of Developmental Paediatrics in Hong Kong: Recent Development

The importance of developmental paediatrics in the rehabilitation of children with disabilities was established in 1977 when the Hong Kong Government, upon the advice of Professor K S Holt (Director of Wolfson Centre, Institute of Child Health, University of London), implemented the White Paper on Comprehensive Observation Scheme for early identification of children with developmental delays. This is a monumental milestone for Developmental Paediatrics in Hong Kong because this is the year the Medical and Health Department of the Hong Kong Government inaugurated two major events in Hong Kong: *Universal Developmental Screening Tests for all Preschool Children in Hong Kong* at the Maternal Child Health Centres free of charge under the then Principal Medical Officer Dr. Betty Eo-Yang, and the grand opening of the first multidisciplinary *Child Assessment Centre at Arran Street* to provide developmental assessment for children with developmental problems. Dr. Lillian Ko was the first Consultant-in-Charge of the Centre and succeeded by Dr. Rose Mak for another 18 years with outstanding achievements. Dr. Catherine CC Lam is currently Consultant-in-Charge of Child Assessment Service and has significantly revamped the Service to meet challenges and needs of the Hong Kong community in the 21st century.

Universal Developmental Screening Tests in a Community

From the results of the Ad-hoc Longitudinal Developmental Study by Field and Baber, a *screening test* based on the format of the Denver Developmental Screening test (of Frankenberg et al) for the first 3 years was compiled with the format modified to correspond with "the Woodside System" of JH Barber of Glasgow. This system, designed by Chan, Baber and Hutchison from the Department of Paediatrics, The University of Hong Kong and known as the "*Hong Kong Developmental Screening System*", was launched officially in Hong Kong in 1982 for use in all Maternal and Child Health Centres. More than 100,000 children received these screening tests annually over the past twenty-five years. Analysis of screening data yielded encouraging results and successful outcome achieving the ultimate objectives of early identification of children with developmental delays! The Test successfully put Hong

Kong onto the world map of child health in that it is one of the few screening tests to be launched on community basis and that it is the ***ONLY test given free of charge*** to all babies at preschool age globally. It remains one of the great achievements jointly hosted by local paediatricians and the Hong Kong Government.

Developmental Assessment Service in Hong Kong

When the first Child Assessment Service was first inaugurated, the Arran Street Child Assessment Centre had only 2 doctors seconded from a paediatric unit of the Queen Elizabeth Hospital. In addition to providing clinical service, the assessment centre undertook teaching of medical students and postgraduate training of doctors in paediatrics. Assessment tools and parent education packages suitable for local use were also developed. By May 2005, there were a total of 8 assessment centres in Hong Kong, 7 of which being run by the Department of Health of the Hong Kong SAR Government under Consultant Paediatrician Dr. Catherine CC Lam and the other one at Sandy Bay by the Department of Child and Adolescent Medicine of The University of Hong Kong under Professor Virginia Wong.

Scope of developmental paediatrics also grew in response to society's demands for quality of survival and to growth of current medical knowledge. In addition to the traditional (more physical) aspects of development, the child's psychological and social development also received due attention. The "holistic" approach was further pursued by including consultations by visiting specialists (such as ophthalmologists, clinical geneticists), joint consultative clinics (with paediatric neurologists, paediatric psychiatrists, orthopaedic surgeons, ENT specialists) as well as by increasing liaison with other clinical units and the plethora of rehabilitation services in Hong Kong. Rehabilitation of the child with special developmental needs (formerly known as chronic disabilities), while still based on child development principles, shifted from dependence on professionals to the empowering of parents. To this aim, toy and parent resource libraries were set up, parent support and parent self-support groups were conducted, and parents were given guidance through seminars, workshops and telephone consultations with good rapport.

It is most unfortunate that the good liaison and cooperation between assessment centres and hospital paediatric units suffered a serious setback when in 1989 the Medical and Health Department was bifurcated into the Department of Health (to which the seven government assessment centres belong) and the Hospital Authority (to which the other assessment centre and hospital paediatric units belong). Such a severance, brought about by short-sighted and inexperienced bureaucrats, hampered significantly the close communication and coordination between the two closely-linked components of the service essential for the proper functioning of the subspecialty of developmental paediatrics. History will bear witness to the detrimental effect on the optimum development of the subspecialty created by such misguided administration change without consultation of the profession!

The Hong Kong Society of Child Neurology and Developmental Paediatrics

The Hong Kong Society of Child Neurology and Developmental Paediatrics started as an "interest group" in 1992 and officially inaugurated in April 1994 with the objectives to promote the standard of practice and professional image of the two subspecialties of child neurology (CN) and developmental paediatrics (DP), to provide assistance to and cooperate with other medical

professionals, and to act as advocates for children suffering from diseases related to the subspecialties of CN and DP.

Since its inauguration ten years ago, the Society has made significant contributions to the subspecialties of child neurology and developmental paediatrics via its regular scientific activities and public lectures by guest speakers (and thereby also providing excellent opportunities for continuing medical education). The Society strove to establish a central registry for local diseases within the subspecialties and endeavour to promote collaborative research efforts among clinical units. It created joint consultative clinic conferences for discussing clinical problems, reviewed current practice and standards for the two subspecialties in Hong Kong, published *Brainchild* (Society's official professional publication) and Manuals on Child Neurology and Developmental Paediatrics respectively, as well as provided advice and recommendations to the Hong Kong College of Paediatricians regarding both basic and higher training within our subspecialties. In addition to such heavy engagements in professional affairs, the Society has been proactive in realizing its role as child advocate. Its effort and achievements on "Myoblast Transplant in Duchenne Muscular Dystrophy", "Rights and Welfare for Children with Specific Learning Disabilities (SLD) and "Iodination of Table Salts in Hong Kong" all bear permanent testimony of the Society's dedications. Throughout these years, the Society worked as one functional unit, and has the unique feature whereby activities served to bridge the gap between paediatricians practising within institutions and in the private sector: a most cost-effective way to utilize local manpower and resources establishing good prototypes for harmonious collaboration and cooperation between the two sectors in Hong Kong. The Society is very proud of its progress and achievements and is confident that, with determination and dedication, new horizons will be reached for Child Neurology and Developmental Paediatrics in Hong Kong!

Developmental Paediatrics Today: Some Local Statistics in Hong Kong

From the experience of Child Assessment Service of the Department of Health of the Hong Kong SAR Government (7 assessment centres out of total of 8 within the SAR), the number of new cases of children aged between 0 to 12 years requiring developmental assessment rose from 2374 in 1994 to 6439 in 2004. This increase is witnessed against the background of a fall in the number of children aged 0 to 15 years from 1.2 million to 1.04 million during these 10 years. A Central Registry for Rehabilitation (CRR) of Hong Kong was established in 1982 to collect and compile information on people with disabilities in Hong Kong through relevant government departments and non-governmental organizations with a view to providing statistics on disability to Government and NGOs for the planning and delivery of rehabilitation services and research purposes. Registration with the CRR is on a voluntary basis and is known to have serious problems with under reporting. 6542 children 0-14 years old registered with disabilities in 2004, representing 0.63% of the population of this age range, significantly lower than rates quoted for developmental problems today. Categories of disabilities in the 1980's and early 1990's included mental handicap, physical handicap, hearing impairment, visual impairment, mental illness, maladjustment and learning difficulties (referring to a mixed group of children with education difficulties due to low intelligence, specific learning difficulties and transient factors that lead to underachievement in school). These categories largely reflected disabilities that were recognized by and visible to the public. At Arran Street Child Assessment

Centre (ASCAC) of CAS from 1978 to 1982, in children aged 0-11 years with an average of 650 referrals per year, mental retardation was the most common disability occurring in 56.9%, while cerebral palsy occurred in 18.7%, severe-profound hearing loss in 6.4%, autism in 2.6% and blindness in 1.4%. In addition, there were 16.2% with specific speech disorders. 65% of children referred were between 1-4 years, with 88% under 6 years. These revealed the state of assessment and placement needs for children who had severe unmet developmental needs at that time. From 1995, the categories of disabilities in the White Paper on Rehabilitation were revised to also include autism, speech impairment and visual disabilities, while learning difficulties and later maladjustment were excluded. During this period, less visible developmental disorders have become increasingly recognized. While these conditions may not affect the individual in all aspects of basic activities of living, they cause serious disablement and exclusion from participation in important areas of development, including learning and social participation. These include developmental dyslexia (within the SLD group of disorders), attention deficit disorders, and the fuller spectrum of autistic spectrum disorders. In 2004, 6439 children were referred for assessment. 75% of these were under 6 years. Their diagnoses showed a significantly different profile: mental retardation was seen in 8.4%, borderline developmental delay in another 17.7%, language and speech delay and disorders in 30.2%, specific learning disabilities in 12.1%, attention problems and disorders in 10.2%, and autistic spectrum disorders in 8.8%. Traditional serious and visible impairments were found in 0.6% with cerebral palsy, 0.2% with blindness and 0.6% with significant hearing impairment.

Secular changes observed can be ascribed to a number of medical, educational and societal factors. Improvement in prevention of disabling conditions, including through improved prenatal diagnosis, antenatal and perinatal care, effective immunization programmes, injury prevention, early treatment of illnesses such as cataract and infections, have led to progressive decrease in serious disabilities. Increased public awareness of developmental problems and raised expectations by parents and the public have brought forth children with less severe intellectual and behavioural problems. Improvement in professional understanding of conditions such as specific learning disabilities, attention deficit disorders and high function autistic spectrum disorders have allowed earlier and more accurate diagnosis and effective management.

As citizens of a developed city, Hong Kong's children should be provided with the highest standards of health care. Maximizing their development in physical, intellectual and emotional domains is the duty not only of the parents, but also of those taking care of them, and of course of paediatricians who are their guardians and advocates.

Link List:

- 1) Department of Health/HKSAR Government: www.dh.gov.hk
 - a) Child Assessment Service: Tel 2246 6633
 - b) Family Health Service: Tel 2961 8855
- 2) The University of Hong Kong: Duchess of Kent Child Assessment Centre, Tel: 2974 0331
- 3) Social Welfare Department/HKSAR Government: www.info.gov.hk/swd, Tel: 2343 2255
- 4) Education & Manpower Bureau (EMB) /HKSAR Government: <http://serc.emb.gov.hk>, Tel: 28910088
- 5) Hospital Authority: www.ha.org.hk, Tel: 2300 6555
- 6) Heep Hong Society: www.heephong.org, Tel: 2776 3111
- 7) Overseas: www.med.umich.edu/libr/yourchild/devdel.htm

To obtain the list of references please contact author at M-10, Hennessy Centre, 555 Hennessy Road, Hong Kong