

立法會
Legislative Council

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by the Administration)

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Subcommittee on Children's Rights

**Minutes of the sixteenth meeting
on Tuesday, 20 March at 10:45 am
in Conference Room 1 of the Legislative Council Complex**

Members present : Dr Hon Fernando CHEUNG Chiu-hung (Chairman)
Hon SHIU Ka-chun (Deputy Chairman)
Hon LEUNG Yiu-chung
Dr Hon KWOK Ka-ki
Dr Hon Elizabeth QUAT, BBS, JP
Hon Andrew WAN Siu-kin
Hon CHU Hoi-dick
Dr Hon CHENG Chung-tai

Members absent : Hon KWOK Wai-keung, JP
Dr Hon Helena WONG Pik-wan
Hon IP Kin-yuen
Hon Alvin YEUNG
Hon HUI Chi-fung

Public Officers attending : Agenda item I
Dr CHUI Tak-yi, JP
Under Secretary for Food & Health

Miss Linda LEUNG
Principal Assistant Secretary for Food and Health
(Health)2

Dr Rita HO
Principal Medical & Health Officer
(Family Health Service)
Department of Health

Mr Charles LEUNG
Chief Social Work Officer
(Rehabilitation and Medical Social Services)
Social Welfare Department

Dr LEE Tsz-leung
Hospital Chief Executive
Hong Kong Children's Hospital
Hospital Authority

Dr SIN Ngai-chuen
Chief Manager
(Patient Safety & Risk Management)
Hospital Authority

**Attendance by
invitation**

: Agenda item I

The League of Social Democrats

Mr NG Man-yuen
Chairman

Mr LEUNG Kwok-hung

Alliance of Social Democrats

Mr CHOW Nok-hang
Vice chairman

Labour Party

Mr KWOK Wing-kin
主席

The Civic Party

Mr LEE Ka-ho
District Developer of the New Territories West

Hong Kong Alliance for Rare Diseases

Mr TSANG Kin-ping
President

跨代跨齡民生關注及研究

理晴女士
研究質控及研究者

Hong Kong Paediatric Foundation

Mrs Gloria TIEN LUK Sau-kuen
Council Member

Tuberous Sclerosis Complex Association of Hong Kong

Rebecca YUEN
President

The Hong Kong Society for Asylum Seekers and
Refugees

CHOI Fung-yee
Member

Hong Kong Association of Squint and Double Vision
Sufferers

朱艷珍女士
會長

PathFinders

Lisa RINGNER-NAECKTER
Access to Healthcare Programme Manager

Clerk in attendance : Ms Angel WONG
Chief Council Secretary 4(4)

Staff in attendance : Miss Mandy NG
Council Secretary 4(4)

Ms Sandy HAU
Legislative Assistant 4(4)

Action

I. Rights of ailing children and expectation on Hong Kong Children's Hospital

(LC Paper No. CB(4)750/17-18(01) -- Paper provided by the Administration)

Written submissions from deputations not attending the meeting

(LC Paper No. CB(4)750/17-18(03) -- Submission from Hong Kong Patients' Voices (*Chinese version only*)

LC Paper No. CB(4)782/17-18(04) -- Submission from Health in Action (*Chinese version only*)

The Subcommittee deliberated (index of proceedings attached at **Annex**).

2. The Subcommittee received views from 12 deputations/individuals attending the meeting and two written submissions from deputations which had not attended the meeting. The major views and concerns of deputations/individuals were summarized as follows:

Rights of ailing children

- (a) according to Article 24 of the United Nations Convention on the Rights of the Child, every child had the right to have good quality of health. The Administration should ensure that all children in Hong Kong, including young offenders, refugees and asylum seeking children, children of foreign domestic helpers and children with special education needs, had equal access to medical services;
- (b) the setting and environment of paediatric wards should be furnished according to the needs of the children and their families. Children's privacy should be duly respected. Overnight stay rooms should be provided so that parents could stay with their children in hospitals. Children and their parents should be informed of the progress of the medical treatment and involved in decision making. Children admitted to hospitals should not be deprived of the right to learn and play;
- (c) the Administration should formulate a comprehensive child-health policy and enhance the community paediatric care to cater for the physical and mental well-being of children;

Action

- (d) to strengthen preventive care for children, the Childhood Immunization Programme for new born babies should cover vaccines for seasonal influenza, human papilloma virus and rotavirus;
- (e) consideration should be given to issue rehabilitation services voucher to children with vision problem, such as squint and double vision, for purchasing corrective glasses;
- (f) the Administration should put in place measures to ease manpower strain in public hospitals, such as increasing the recurrent expenditure of the Hospital Authority ("HA") to improve the remuneration of healthcare staff, and exploring the feasibility of recruiting overseas doctors;
- (g) the Administration should take steps to enhance hospital education services, medical social services, rehabilitation services and counseling services for paediatric patients;

Hong Kong Children's Hospital

- (h) with the service commissioning of the Hong Kong Children's Hospital ("HKCH"), it was high time to formulate a specific policy to cater to the needs of rare disease children suffering from rare diseases. A one-stop centre to diagnose, treat and educate children suffering from inborn rare diseases should be set up. Transitional care should be enhanced to ensure patients' smooth transition to other medical departments when they reached 18. Moreover, there was a dire need to set up a rare disease database to facilitate relevant clinical research development and professional training;
- (i) HKCH should draw up timeline for migrating to full services;
- (j) the Administration should formulate performance indicators to monitor the operation of HKCH. Patients groups, child concern groups, parents and children should be included on the membership of HKCH's Hospital Governing Committee ("HGC") to ensure adequate representation;
- (k) HKCH should provide special care dentistry services to children who could not receive routine oral care services due to physical, intellectual, mental and medical issues; and

Action

- (1) the Administration should ensure adequate public transport facilities and services to dovetail with the service commissioning of HKCH.
3. Having regard to the views expressed by the deputations, members were concerned about HKCH's manpower, facilities, planning and clinical services. They stressed the importance of including patient groups, child concern groups, parents and children in HGC of HKCH so as to provide adequate representation. They also see a need for the formulation of a policy to help children with rare diseases.
4. On the views and concerns raised by members and deputations at the meeting, the Administration made the following responses:

Rights of ailing children

- (a) the Administration was mindful to provide medical services to all children. For non-refoulement minors who required subvented pre-school rehabilitation services, the Social Welfare Department would make timely arrangement following the prevailing mechanism. Upon receiving confirmation from the Immigration Department ("ImmD") that there was no objection to allowing these children to receive pre-school rehabilitation services, they would be put on the waiting list of the services and be eligible for applying training subsidy. For squint and double vision sufferers, the Administration would explore possible ways to support them under the existing public healthcare system;
- (b) the Administration would increase the recurrent funding for HA progressively on a triennium basis to enable HA to plan its service in a more effective and sustained manner. The University Grants Committee would review the number of medical, nursing and allied health school places on a triennium basis and increase these school places to match with the changing demands in the society;

Clinical services of Hong Kong Children's Hospital

- (c) HKCH was built with a planned capacity of 468 inpatient and day beds to cope with the projected service demand for the next 10 years. Taking into account manpower availability and resources support, HKCH would commence its services by phases to ensure patient safety, quality of service and smoothness in operation. In its first phase of service commencement, 230 inpatient and day beds would be provided;

Action

- (d) upon its service commissioning, HKCH would serve as a tertiary referral centre for complex, serious and uncommon paediatric cases requiring multidisciplinary management, providing diagnosis, treatment and rehabilitation services for needy patients from birth to 18 years of age territory-wide. The existing 13 paediatric departments in regional public hospitals would continue to provide secondary, acute, emergency and community paediatric care. Under this hub-and-spoke model, HKCH and regional hospitals would work together to form a coordinated and coherent paediatric service network in HA, enhancing the quality of the overall public paediatric services;
- (e) HKCH would pool together advanced equipment, experts and relevant support to strengthen research and training regarding paediatric and genetic diseases. The Clinical Genetic Service of the Department of Health would move into HKCH in 2019. In future, the laboratory tests, diagnosis and family counselling of all relevant diseases would be concentrated at HKCH. The healthcare team would make necessary arrangements as far as possible, e.g. follow-up consultations for different specialties on the same day at HKCH to reduce the inconvenience to patients and their parents;
- (f) there was no internationally agreed definition of rare diseases as it varied among countries depending on different healthcare systems. Notwithstanding this, the Administration had taken steps to support these patients, for instance, introducing new drugs and medical treatment to Hong Kong. In December 2017, the Food and Health Bureau set up a Steering Committee on Genomic Medicine which would put forward its recommendations in the development of genomic medicine in two years' time;

Manpower of Hong Kong Children's Hospital

- (g) healthcare professionals joining HKCH through advanced recruitment had undergone local and/or overseas training to cater for the preparation for phased service commissioning of HKCH. Provision of training for healthcare professionals working in related specialties and sub-specialties would continue in the coming years;
- (h) healthcare staff of HKCH were now attached to various public hospitals. Since they had been spending all or most of their time managing children with related diseases, HA would make necessary arrangements so that their translocation to HKCH would not cause significant impact on other services at the regional hospitals;

Action

- (i) HKCH had recruited an expert in inborn errors of metabolism to provide dedicated support to patients suffering from related rare diseases;
- (j) medical social workers of HKCH would provide timely psycho-social intervention to paediatric patients and their families. A group of passionate volunteers from patient groups and non-governmental organizations would also arrange various activities to cater for the emotional needs of paediatric patients;

Facilities and support services of Hong Kong Children's Hospital

- (k) HKCH adopted a children-centred and family-friendly design to create a better patient experience. Its home-like environment could relieve the fear and stress of child patients. There were various facilities in the hospital to support the care, leisure and social needs of patients and their family, such as, playing areas, parents' quarters and family pantries, etc.;
- (l) HKCH was equipped with research laboratories, clinical laboratories, clinical trial centre, simulation training centre, auditorium, etc. to facilitate clinical research development and professional training;
- (m) HKCH had liaised with the Hong Kong Red Cross Hospital Schools to enhance teaching for paediatric patients. The multi-media classroom in HKCH would provide a pleasant learning environment;
- (n) HKCH would continue to communicate with relevant government departments with a view to strengthening its transport accessibility to tie in with its service commissioning;

Governance of Hong Kong Children's Hospital

- (o) HKCH would conduct clinical audit to monitor its surgical outcomes and put in place assessments to track its patients' experience and satisfaction; and
- (p) like other public hospitals, HA had set up a HGC for HKCH under the established mechanism. The appointees possessed appropriate experience and expertise, including service to other HGCs, rich experience in management, community engagement and fund-raising, as well as passion in healthcare services.

Action

5. The Subcommittee requested the Administration to provide the following information:
 - (a) the training records of medical, nursing and allied health staff of the HKCH in the past three years;
 - (b) the justifications for building HKCH with a planned capacity of 468 inpatient and day beds to cope with the projected service demand for the next 10 years;
 - (c) HKCH's timeline for migrating to full service;
 - (d) HKCH's projected recurrent expenditure; and
 - (e) the appointment mechanism, membership, terms of reference and work plan of HGC of HKCH.

(Post-meeting note: The Administration's written information was issued to members vide LC Paper No. CB(4)887/17-18 (01) on 9 April 2018.)

II. Any other business

6. There being no other business, the meeting ended at 12:51 pm.

Council Business Division 4
Legislative Council Secretariat
26 July 2018

Subcommittee on Children's Rights
Proceedings of the sixteenth meeting
on Tuesday, 20 March 2018 at 10:45 am
in Conference Room 1 of the Legislative Council Complex

Time marker	Speaker(s)	Subject(s)	Action required
<i>Agenda Item I - Rights of ailing children and expectation on Hong Kong Children's Hospital</i>			
000900-001222	Chairman	Opening remarks	
001223-001525	Chairman The League of Social Democrats	Presentation of views	
001526-002043	Chairman Mr LEUNG Kwok-hung	Presentation of views	
002044-002353	Chairman Alliance of Social Democrats	Presentation of views	
002354-002360	Chairman Labour Party	Presentation of views	
002361-002934	Chairman Civic Party	Presentation of views [LC Paper No. CB(4)804/17-18(01)]	
002935-003250	Chairman Hong Kong Alliance for Rare Diseases	Presentation of views [LC Paper No. CB(4)750/17-18(02)]	
003251-003613	Chairman 跨代跨齡民生關注及研究	Presentation of views	
003614-003941	Chairman Tuberous Sclerosis Complex Association of Hong Kong	Presentation of views	
003942-004522	Chairman The Hong Kong Society for Asylum Seekers and Refugees	Presentation of views	
004523-004833	Chairman Hong Kong Association of Squint and Double Vision Sufferers	Presentation of views [LC Paper No. CB(4)782/17-18(02)]	
004834-005141	Chairman Pathfinders	Presentation of views [LC Paper No. CB(4)782/17-18(03)]	
005142-005746	Chairman Hong Kong Paediatric Foundation	Presentation of views [LC Paper No. CB(4)782/17-18(01)]	
005747-011848	Chairman The Administration	The Chairman's remarks and the Administration's response to the views expressed by the deputations	
011849-012620	Chairman Mr LEUNG Yiu-chung The Administration	Mr LEUNG's concerns about the Hong Kong Children's Hospital ("HKCH"), including its manpower, training, performance indicators and timeline for migrating to full service, etc.	Paragraph 5 of the minutes refer

Time marker	Speaker(s)	Subject(s)	Action required
012621-013452	Chairman Deputy Chairman The Administration	The Deputy Chairman's enquiries about HKCH's children-centred service approach, interior design, recurrent expenditure and Hospital Governing Committee ("HGC")	Paragraph 5 of the minutes refer
013453-014808	Chairman Dr Elizabeth QUAT The Administration	Dr QUAT's views on the clinical services provided for paediatric patients suffering from inborn rare diseases, the importance to set up a database of and formulate a definition for rare diseases	
014809-014840	Chairman Hong Kong Association of Squint and Double Vision Sufferers	Presentation of views	
014841-014938	Chairman Hong Kong Paediatric Foundation	Presentation of views	
014939-015121	Chairman Tuberous Sclerosis Complex Association of Hong Kong	Presentation of views	
015122-015228	Chairman Hong Kong Alliance for Rare Diseases	Presentation of views	
015229-015442	Chairman 跨代跨齡民生關注及研究	Presentation of views	
015443-020006	Chairman The Administration	The Administration's response to the views expressed by the deputations	
020007-020425	Chairman	The Chairman's concern over the absence of rare disease policies	
020426-020508	Chairman Deputy Chairman	The Deputy Chairman's calling on the Administration to provide more resources to facilitate service delivery of medical social workers of HKCH	
020509-021031	Chairman Dr KWOK Ka-ki The Administration	Dr KWOK's calling for a review of the membership of HGC of HKCH	
<i>Agenda Item II – Any other business</i>			
021032-021052	Chairman	Closing remarks	