CHAPTER 10 - SERVICES FOR VISCERALLY DISABLED PERSONS

DEFINITION

10.1 Visceral disability was covered by physical handicap as defined in the 1990 Rehabilitation Programme Plan. Upon the advice of the Hong Kong Medical Association in 1994, physical handicap was re-defined to limit its application to disability affecting an individual’s locomotor function and a new definition was drawn up for visceral disability as any other disabilities arising from diseases affecting the body’s organs.

10.2 The Plan adopts the following definition for a visceraally disabled person -

A visceraally disabled person is a person with disability resulting from diseases or the respective treatment. The disability, not being limited to locomotor functions in nature, constitutes disadvantages or restrictions in one or more aspects of daily living activities.

ESTIMATED NUMBER OF VISCERALLY DISABLED PERSONS

10.3 There is no readily available figure on the total number of visceraally disabled persons in Hong Kong. It has been suggested that overseas prevalence can be adopted for local use. However, overseas prevalence is not a good option as there are differences in the standard of health, social and cultural conditions, etc. between Hong Kong and overseas countries. Thus, the number of patients admitted to local public hospitals for treatment of specific visceral diseases can serve as a reference (see Appendix 1.10 for details). However, it should be noted that not all these patients are disabled or require rehabilitation. In service planning, factors like patients’ type and degree of disability, number of people with visceral diseases who are disabled and efficacy of services should also be taken into consideration.

TYPES OF SERVICES

10.4 Visceraally disabled persons and their families require assistance in a number of areas and a range of support services on top of medical treatment in order to cope with chronic health conditions. The disabling effects on visceraally disabled persons and their relatives take many forms. In many cases, daily activities are much affected by the prolonged suffering. Pain causes emotional stress and a sense of helplessness. Additionally, the finance of the family is also adversely affected and the familial role of the patient may become dysfunctional.

10.5 In meeting the needs of people with visceral disability, a number of approaches can be adopted. These include -

(a) disability prevention, in particular secondary and tertiary prevention;

(b) provision of psychological support to newly diagnosed and exacerbated patients;

(c) well co-ordinated discharge planning for patients and their families;
(d) continuum of services from hospitals to the community as well as holistic care in both hospitals and the community;

(e) promotion of patient self-help groups; and

(f) promotion of community involvement and public education.

10.6 In response to the needs of viscerally disabled persons, the Government and the non-governmental sector have launched a number of new initiatives since the publication of the Green Paper on Rehabilitation in 1992. These include the setting up of patient resource centres in hospitals/institutions under the Hospital Authority; the development of the Community Rehabilitation Network; and the formation of patient self-help groups, many of which are closely affiliated with the Hospital Authority and rehabilitation organisations.

10.7 The major rehabilitation services required by viscerally disabled persons are -

(a) medical rehabilitation;

(b) pre-discharge services;

(c) post-discharge follow-up services;

(d) patients resource centres;

(e) community and patient health resource centre;

(f) education;

(g) community rehabilitation network;

(h) retraining and employment; and

(i) identification and assessment services, other vocational rehabilitation, recreation and sports, and support services provided by the Government and self-help groups which are covered in other chapters.

MEDICAL REHABILITATION

Principles and Policy Objectives

10.8 The ultimate aim of medical rehabilitation is to restore patients’ functional capacity to their maximum potential so that they can live independently and continue to participate in the community as far and as equally as possible. Medical rehabilitation aims to help patients overcome their structural or functional impairments, minimise the residual defects, disabilities or complications, and develop their living skills. Long term institutionalisation should be avoided as far as possible.

Prevention of Visceral Disability and Medical Treatment Services

10.9 The Hospital Authority has identified 10 priority health areas for focused attention. These include cancer, cerebrovascular disease, ischaemic heart disease, end stage renal failure, chronic lung disease and diabetes mellitus. Patients with these diseases are of high risk to become viscerally disabled if not properly maintained. The Hospital Authority will continue to develop specific strategies and programmes to improve the health status and functional outcome of these patient groups. In particular, designated multi-disciplinary
rehabilitation programmes (for examples, cardiac, pulmonary, stroke, renal) are being provided and developed in various hospitals. It is proposed to establish rehabilitation co-ordination teams in every hospital cluster to provide and co-ordinate medical rehabilitation services for patients with chronic diseases. Apart from better integrating acute, extended, ambulatory and community care services, these teams will also improve the collaboration and continuity of care between hospitals and other care-providers.

10.10 The Hospital Authority is of the view that specialised centres for medical rehabilitation should be established to provide medical rehabilitation services to patients with special needs (for example, neurosurgical patients with significant cognitive impairment). These centres will also promote and develop the expertise in medical rehabilitation.

**PRE-DISCHARGE SERVICES**

10.11 Rehabilitation should start early and be well planned. The concept of pre-discharging planning has now been widely practised in many public hospitals. Improving the communication network between hospitals and community service providers is essential to the successful provision of pre-discharge planning services. At present, medical social workers are responsible for referring patients to receive appropriate service. To strengthen the pre-discharge services, a number of new initiatives have been taken forward, including enhancement of the provision of medical social workers, teamwork approach in hospitals, and collaboration with the community sector (for example, the Community Rehabilitation Network). In addition, medical practitioners can act as referral agencies while further improvement in communication between the medical and community setting is necessary.

**POST-DISCHARGE FOLLOW-UP SERVICES**

10.12 A variety of services are available to assist patients who have been discharged from hospitals but who still require nursing care, support or assistance. The major ones include -

(a) **Community Nursing Service** - this is delivered through a network of nursing centres and stations of the Hospital Authority with the mission to provide quality nursing services to patients in their own environment. A service brief with details on the objective, scope of service, staffing level, referral channel and clientele is at Appendix 5.2;

(b) **Community Occupational Therapy Service** - this is provided by the Hospital Authority and formerly known as domiciliary occupational therapy service. It aims at providing occupational therapy service in patients’ living environment to help them perform daily living tasks. A service brief with details on the objective, programme, staffing level, referral channel and clientele is at Appendix 5.1;

(c) **Domiciliary and Community Physiotherapy Service** - this is provided by the Hospital Authority with an aim of providing physiotherapy home programs to maintain or restore patients’ mobility and physical ability so as to facilitate their re-integration. A service brief with details on the objective, programme, referral channel and clientele is at Appendix 5.3;
(d) **Medical Social Service** - this is provided by the Hospital Authority and Social Welfare Department with a view to assisting patients and their families in dealing with problems arising from illness/disabilities. A service brief with details on the objective, programme, staffing level, referral channel and clientele is at Appendix 4.21; and

(e) **Speech Therapy Service** - this is required for some people with visceral disability such as those suffering from stroke, cancer, brain injury and Parkinsonism. With the co-operation of the Hospital Authority, a non-governmental organisation (NGO) launched a one-year pilot project known as “Train the Trainers for Laryngectionized Patients” in October 1996. Under this pilot project, speech therapists from the Hospital Authority offered training to the NGO’s voluntary tutors who in turn helped the NGO’s members who had speech problems. The non-governmental sector recommended that this “outreach model” should be used to help other needy groups.

**PATIENT RESOURCE CENTRES**

10.13 It is important to enhance and support the role of patients, their families and the community as carers. Up to December 1998, 29 patient resource centres had been set up in the hospitals/institutions under the Hospital Authority to act as the focal point to provide such support, and to facilitate the formation of self-help groups and community linkages. These centres serve hospital in-patients and out-patients with various chronic diseases, their family members as well as the general public. They mainly focus on the promotion of self-care and self-help of discharged patients rather than the provision of direct services such as psychosocial support or psychological counselling. Patients with suitable condition will be referred to community carers for continuous care. Co-operation and partnership between patient resource centres and other community support services including the Community Rehabilitation Network exist and the interface will be further enhanced. A service brief with details on the objective, programme and clientele of the patient resource centre is at Appendix 5.4.

**COMMUNITY AND PATIENT HEALTH RESOURCE CENTRE**

10.14 The Hospital Authority established a community and patient health resource centre in mid-1998. The centre serves as a springboard for the Hospital Authority’s collaboration with patient self-help groups and the community in the health care process and a gateway for vicerally disabled persons and the public to obtain information concerning health and the Hospital Authority. It also serves as a focal point for health education activities to empower vicerally disabled persons, their families and the community at large with the knowledge and skills to take up patient care and look after one’s own health. A service brief with details on the role, facilities and operation is at Appendix 5.5.
EDUCATION

Policy Objectives

10.15 School-age viscerally disabled children should receive education according to their specific needs caused by their disabilities. The policy objectives in this regard are as follows -

(a) viscerally disabled children are provided with nine years of universal basic education, some may receive a longer period of education. Thereafter, facilities are provided in accordance with the general expansion of senior secondary education for those who are capable of receiving such education; and

(b) viscerally disabled children are encouraged to receive education in ordinary schools as far as possible. Supportive services are provided either by the Education Department or by schools as necessary to facilitate their integration. For those who cannot be integrated in ordinary schools, they are placed in special schools.

Integrated Education in Ordinary Schools

10.16 Viscerally disabled children are encouraged to receive education in ordinary schools. The Education Department will provide support services to facilitate their integration as and when necessary. Remedial teaching, counselling, and advice on rehabilitation aids and resources are given to viscerally disabled children attending ordinary schools under the Resource Help Service. The service comprises -

(a) remedial teaching service - for viscerally disabled children who are backward in basic subjects, remedial teaching service will be provided for them at resource teaching services centres outside school hours;

(b) peripatetic teaching service - for viscerally disabled children who, for various reasons, cannot receive remedial teaching service at resources teaching services centres, peripatetic teaching service will be provided for them in their respective schools; and

(c) follow-up service - for those viscerally disabled children who have made reasonable progress and no longer need resource help service, follow-up service in the form of telephone contacts will be provided to ensure smooth integration.

Special Schools

10.17 Viscerally disabled children may attend special schools for disabled children according to their special education needs. Details on the provision of special schools for disabled children are provided in the respective chapters on services for disability groups.
Hospital School

10.18 As at December 1998, there was a hospital school providing 345 places (excluding 120 places for psychiatric beds), with 285 at the primary level and 60 at junior secondary level, in 15 hospitals and medical rehabilitation centres. The average unit cost of these places in the school year 1997/98 was $4,356 per month. The primary objective of the hospital school is to provide education to hospitalised children who are excluded temporarily from normal classes. The hospital school programme ensures equal educational opportunities for these children and helps them resume normal schooling upon discharge. The Education Department will continue to work closely with the hospital school to render professional support and review the service as appropriate.

COMMUNITY REHABILITATION NETWORK

10.19 Community based rehabilitation is considered as an effective means in helping people with disabilities and their families to continue to have quality life in their own home and the community. The Government, in close partnership with NGOs, initiated community based rehabilitation in the late 1980s in public housing estates, which led to the development of the Community Rehabilitation Network (CRN).

10.20 The objective of the CRN is to enhance the quality of life of viscerally disabled persons and their families in their own homes and the community through the promotion of self-help and the organisation of psychosocial support and educational services. The CRN works in close collaboration with over 30 hospitals, 60 community and self-help organisations as well as various government departments. The services are provided by a multi-disciplinary professional team in conjunction with over a thousand professionals, patients and lay volunteers. Patients and family members are also an essential part of the team.

10.21 In early 1994, the former Royal Hong Kong Jockey Club approved a grant of about $24 million to meet the recurrent expenditure of one clearing house and two regional centres of the CRN in Hong Kong Island and Kowloon East for their first two years of operation as a pilot project. The clearing house and the two regional centres started operation in 1994. According to the 1995 White Paper on Rehabilitation, the Administration would consider subventing the clearing house and a total of five CRN centres subject to the findings of an evaluation of the pilot project and the availability of resources. The pilot project was extended for one year with support from the Lotteries Fund. After evaluating on the effectiveness of the pilot project, the Administration then turned the project to subvention in April 1997 together with the establishment of the third regional centre in Kowloon West. The average amounts of subvention per regional centre and clearing house in 1997-98 were $465,580 and $153,508 per month respectively.

RETRAINING AND EMPLOYMENT

10.22 In helping viscerally disabled persons integrate into the community through gainful employment, some NGOs organise vocational retraining programmes with support from the Employees Retraining Board. Some hospitals under the Hospital Authority provide vocational rehabilitation programmes, of which many are organised in collaboration with other organisations. For example, the Patient Retraining and Vocational Resettlement
Service is jointly organised by the Employees Retraining Board, Queen Elizabeth Hospital and Kowloon Hospital with the support from the Selective Placement Division of the Labour Department, Vocational Training Council and an NGO. The Vocational Training Council provides vocational assessment and training services to viscerally disabled persons through referrals by medical social workers. The Selective Placement Division of the Labour Department provides free employment services to people with disabilities, including viscerally disabled persons, seeking open employment. Details on retraining and employment services for people with disabilities are provided in the chapter on vocational rehabilitation.

OTHER SERVICES IN THE COMMUNITY

10.23 Many organisations in the community are involved, directly or indirectly, in the provision of various educational and support services to viscerally disabled persons. These efforts are recognised as important contributions to meeting the needs of viscerally disabled persons. They include -

(a) health education programmes organised by various associations, such as self-help organisations, hospitals, patients resource centres and various professional groups;

(b) support services, such as hospital visits and self-care training, offered by self-help organisations;

(c) financial and professional support from various disease specific organisations such as the Hong Kong Cancer Fund and the Hong Kong Children Cancer Foundation; and

(d) volunteers support programmes provided by NGOs and hospitals.

ISSUES OF CONCERN

10.24 While the Administration has been subventing the operations of three CRN centres and a clearing house since April 1997, chronically ill persons and their carers have been urging the Administration to subvent two additional regional centres. However, there has been rapid development of patient resource centres under the Hospital Authority and other support services over these years. In view of this, the Administration commissioned a consultancy study in 1998 to review the cost-effectiveness of existing CRN operation and its interface with similar services provided by the Hospital Authority, the Social Welfare Department and the Department of Health, and to recommend future development of the CRN service. The consultancy study was completed in January 1999 and concluded that the CRN was cost-effective and able to meet the needs of most chronically ill patients. The consultants also recommended a number of changes to the scope and mode of delivery of the CRN service. The Administration is considering the recommendations.