

Ref : CB2/PL/WS

Panel on Welfare Services

Background paper prepared by Legislative Council Secretariat

Support and assistance for tetraplegic patients living in the community

Purpose

This paper gives an account of the past discussions by the Panel on Welfare Services (the Panel) on the support and assistance for tetraplegic patients living in the community.

Background

2. Press coverage of the case of "Pun Tsai" in April 2004 aroused much public concern over the plight of tetraplegic patients. The Panel invited four self-help groups ("the self-help groups"), namely, Hong Kong Neuro-Muscular Disease Association, 1st Step Association, Paraplegic & Quadriplegic Association and Direction Association for the Handicapped, to give their views on financial assistance and support and training for the tetraplegic patients and their families on 10 May 2004.

Major concerns raised and the suggestions made by the self-help groups

3. At the meeting of the Panel on 10 May 2004, the self-help groups pointed out that the monthly standard payment rates under the Comprehensive Social Security Assistance (CSSA) Scheme and the disability allowance under the Social Security Assistance Scheme were not adequate to meet the special needs of tetraplegic patients living in the community. Although tetraplegic patients on CSSA could apply for special grants under the CSSA Scheme to cover one-off and recurrent costs of medical consumable items and rehabilitation appliances, the actual amount of money spent by the tetraplegic patients often far exceeded the costs of the items concerned based on medical recommendation due to differences in the doctors' perception of the patients' needs and the actual needs of the patients. The self-help groups also pointed out that while there were several charitable funds which tetraplegic patients not on CSSA could apply for financial assistance, the lack of transparency of the operation of these funds, and the generally one-off nature of such grants, had deterred these patients from applying for these funds. The self-help groups called upon the Administration to provide tetraplegic patients living in the community with a monthly allowance of \$5,800 to cover costs of medical consumable items and rehabilitation appliances.

4. The self-help groups told the meeting that the Home-based Training and Support (HBTS) Services operated by the Social Welfare Department (SWD), which provided occupational therapy and physiotherapy services to severely disabled persons as well as training for their families, fell short of relieving the heavy workload of their carers. As tetraplegic patients required round-the-clock care, the self-help groups called upon the Administration to provide this group of patients with an additional monthly allowance to hire a carer or subsidise those family members who gave up their jobs to care for them.

5. The self-help groups also urged the Administration to conduct an overall review of the support and assistance for tetraplegic patients living in the community, including setting up dedicated residential care homes for severely disabled persons of normal intellect and mental state; creating a barrier-free environment for people with disabilities; and establishing an inter-departmental comprising representatives the committee from relevant policy bureaux/Government departments and representatives of disability groups to regularly monitor the adequacy and effectiveness of the support and assistance provided to tetraplegic patients.

6. The Panel expressed support for the suggestions made by the self-help groups, and urged the Administration to expeditiously implement the requests mentioned in paragraphs 3 and 4 above. The Panel noted that if tetraplegic patients were forced to reside in hospitals due to their not having anyone to care for them at home, each case could cost the taxpayers between \$90,000 and \$180,000 a month. Hon CHOY So-yuk also asked the Administration to allocate more resources to provide training to carers and to provide assistance enabling tetraplegic patients to modify their homes to suit their special needs.

The Administration's response

7. The response of the Administration to the concerns/requests of the self-help groups and members at the meetings of the Panel on 10 May 2004 and 19 July 2004 is summarised as follows -

- (a) the Buildings Department is presently reviewing the barrier-free guidelines on building design for further improving accessibility for people with disabilities. Consultation with the building industry and representatives of disability groups on the revised guidelines would be conducted before implementation;
- application procedures for special grants to cover expenses of the (b) patients have been streamlined tetraplegic to enhance communication and facilitate processing among professionals. These include new referral forms exclusively for special grants to cover medical consumable items and rehabilitation appliances as well as Care and Attention (C&A) Allowance. In order to handle CSSA cases involving tetraplegic patients in a more consistent and coordinated manner, Social Security Field Units (SSFUs) of SWD have arranged to assign these cases to a designated team. Coordinators in individual SSFU have also been appointed for this purpose;
- (c) SWD will adopt a more flexible approach in granting C&A Allowance to tetraplegic patients, in recognition of the difficulties faced by their families in looking after these patients who may require 24-hour care and attention at home. For justifiable cases, consideration can be given to granting the C&A Allowance to hire a full-time or part-time carer to assist in providing personal care to the tetraplegic patient;
- (d) Integrated Home Care Services for frail elders would be extended to severely disabled persons in August 2004 to provide holistic care and support services to these persons according to their individual needs, ranging from meals, home-making and nursing care;
- (e) medical social workers (MSWs) in public clinics/hospitals and social workers of Integrated Family Services Centres provide counselling support to the tetraplegic patients and their families to assist them overcome the difficulties encountered. They will also be referred for psychological services from clinical psychologists where necessary;

- (f) medical specialists of the Hospital Authority and occupational therapists (OTs) of the Home-based Training and Support Teams provide tetraplegic patients with information about the needed rehabilitation appliances/aids and advice/recommendations on home modifications to facilitate them to live in the community. For tetraplegic patients living in public housing estates, the Housing Authority would be responsible for the home modification items recommended. For non-public housing tenants on CSSA, they would be assisted under the CSSA Scheme. For the other patients requiring financial assistance in home modification, they may apply for relevant charitable funds through MSWs; and
- (g) prior to discharge from hospital, a multi-disciplinary team in the hospital will assess the rehabilitation needs of individual patients so as to prepare them for the discharge. Physiotherapists (PTs) and OTs will conduct carer training to enable the carers to acquire the knowledge essential for the caring of the patient at home. Day training or home visitation will be provided by PTs and OTs to provide continual support to the carers if required. There are other training programmes for carers provided through mutual help groups and the HBTS Services. Efforts will continue to be made by the Administration to encourage service operators to strengthen training and support for the carers with a view to enhancing independent living of the tetraplegic patients.

Deliberations on the Administration's response

8. Panel members welcomed the move made by SWD to grant a C&A Allowance of \$4,296 per month to tetraplegic patients on CSSA to hire a carer even if the patient concerned had a family member available to provide help at home. Some members pointed out that the amount of allowance was not sufficient to hire an overseas domestic helper, and urged the Administration to lift the ceiling on the C&A Allowance for this group of patients.

9. The Administration explained that the C&A Allowance was intended to provide the flexibility to hire a full-time or part-time carer to relieve and assist in providing personal care to the tetraplegic patient on CSSA. Tetraplegic patients who were not eligible for CSSA might apply to relevant charitable funds through MSWs, patients' mutual help groups or voluntary organisations for subsidy to buy medical supplies and daily necessities. For patients not receiving the C&A Allowance, a disabled adult aged under 60 could receive a monthly CSSA

payment of \$3,720 if he/she lived alone or \$3,375 if he/she lived with his/her family. Tetraplegic patients not receiving CSSA were eligible for a Higher Disability Allowance of \$2,240 per month.

10. In response to Hon LEE Cheuk-yan's query as to how a tetraplegic patient could employ an overseas domestic helper if he/she could not produce income proof to the Immigration Department (ImmD), the Administration advised that SWD was under discussion with ImmD on waiving such requirement for this group of patients.

11. Panel members were of the view that it was not ideal for non-CSSA tetraplegic patients to rely on the support from charitable organisations, and urged that the C&A Allowance be extended to cover this group of patients.

12. In response to Hon CHOY So-yuk's enquiry as to whether consideration could be given to continuing to allow tetraplegic patients to receive the C&A Allowance if they chose to reside on the Mainland, the Administration agreed to consider such proposal upon request on a case-by-case basis.

Recent developments

13. The Administration provided a paper for the meeting of the Panel on 10 January 2005 on the latest progress made in the enhanced services provided to tetraplegic patients living in the community, which is summarised as follows -

- (a) in addition to the C&A allowance, SWD will also consider discretionary grant to cover other one-off expenses related to the hire of helper (including insurance, agent fee, air ticket, government tariff and long service award);
- (b) with effect from 1 November 2004, an Enhanced C&A Allowance was introduced to tetraplegic patients who have fully met the eligibility requirements for receiving the C&A Allowance under the CSSA Scheme. The Enhanced C&A Allowance includes a monthly special addition of \$1,115 which is meant to meet additional out-goings required by these patients;
- (c) the Yan Chai Hospital Board has established a charitable fund named "Yan Chai Tetraplegic Fund" in September 2004 to provide financial assistance to tetraplegic patients for supporting their living in the community and improving their quality of living. The coverage of the grant includes essential expenses for the purchase of

medical/rehabilitation appliances and repair service for these items; the essential expenses on home modifications; temporary grants for the tetraplegic patients in coping with special needs (e.g. personal helper, occasional care, medical consumable items, escort service, personal care items etc.); and other special grants which the Fund Committee considers appropriate in supporting the community living of tetraplegic patients; and

(d) to address the housing need of the tetraplegic patients who wish to live and integrate into the community, the Housing Department (HD) has agreed to give special consideration to Compassionate Rehousing application of tetraplegic patients on their needs for extra space for accommodating the carers and rehabilitation equipment. With the joint effort of medical and allied health team of Kowloon Hospital, a specification on the housing provision, including minimum size, suitability for home modification, accessibility as well as availability of suitable commercial and communal facilities has been worked out to facilitate HD to identify suitable flats for allocation to tetraplegic patients.

Due to time constraint, the discussion of the aforesaid Administration's paper was deferred to the next regular meeting of the Panel on 18 February 2005.

14. In his 2005 Policy Address delivered on 12 January 2005, the Chief Executive announced the Administration's plan to provide CSSA recipients suffering from 100% disability or requiring constant attendance with an additional monthly supplement of \$100 to support them to live in the community. It is estimated about 50 000 CSSA recipients in these categories may benefit from this enhancement, which is planned for implementation within 2005.

Relevant papers

15. Members are invited to access the LegCo website (http://www.legco.gov.hk) to view the minutes of meetings of the Panel held on 10 May 2004 and 19 July 2004 and the papers provided by the Administration.

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