

# SAHK

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**Abstract: Cerebral palsy is caused by an insult to an immature brain, resulting in a lifelong, functional disability. Habilitation for cerebral palsy has previously been focused on the early intervention. However, a majority of the cerebral palsied has not yet attained their maximal potential in adulthood. Most of them are institutionalised in day centres and hostels. In the Spastics Association, the ultimate goal of habilitation is to enhance upward mobility for an independent life. The habilitation process should be extended to the adult clients through the process of progressive deinstitutionalisation. The progression from the constrained, prescriptive, dependent and extrinsically rewarded environment to the independent, self regulated and intrinsically rewarded environment constitutes what we called striving for independence of the cerebral palsied.**

## **Upward Mobility**

In Hong Kong, habilitation of the cerebral palsied starts once the diagnosis is made. The Spastics Association of Hong Kong provides services for cerebral palsied persons ranging from the infant stage to adulthood. Most people have the misconception that sheltered workshops and hostels are the final placement for these clients. In fact, the adult service of the association comprises more than 9 types of centres and services which have been divided into different levels. Centres at each level call for a different level of functioning of its clients. These centres or services have been grouped into 3 vocational, residential and recreational categories. All these centres and services established a longitudinal system which provides ladders for the cerebral palsied adults to practice upward mobility. Individual levels of centres or services represent the rungs of the ladders which allow their clients to realise a gradual but progressive upward movement for an independent life.

The longitudinal system of the adult service (figure 1) provides extended routes for preparing the potential clients for gaining access into the community and further development their higher intellectual and psychosocial functions. The mission of the adult service is to enhance our clients' upward mobility towards an independent life and to promote their integration into the community at each level of the upward movement.

This paper focuses mainly on the upward mobility in the residential route. The ladder of the residential route is composed of 4 rungs. They are represented by the care centres, big hostels, semi-independent hostels and independent homes.

The care centre accommodates severely handicapped clients who are unable to participate in work and self care activities and training. The large hostel accommodates clients who have motivation to work and require training in personal self care and in play skills. The semi-independent hostel provides training in instrumental self care and emphasises hobbies and interests development. It demands the clients have basic work skills and personal self care skills. The independent home accommodates 2-3 clients in an apartment of a public estate. Clients of the independent home are

expected to tackle real-life challenges which call for independence of individual clients and interdependence among flatmates. If the clients are well prepared to live together, they will apply for compassionate rehousing and be discharged from the adult service. In fact, the successive levels of the longitudinal system represent a progressive de-institutionalisation which demands that clients have higher level of independence in the higher-level hostels.



Figure 1. The 3 ladders of upward mobility in the adult service of the Spastics Association of Hong Kong.

### **Integration into the Community**

In our habilitation model, integration is different from upward mobility. We define integration as the mutual respect and understanding between the group identity of the general public and the cerebral palsied (Leung & Su, 1995). The emphasis is not on the normalisation, for our clients to reach the standards of the general public or to function in the environment that is designed for ordinary people. Instead, we focus on assisting our clients to utilise their abilities, to establish their own standards and to function fruitfully in an environment that is specially designed for them. These standards and the specially designed environment should gain the respect of the general public and the government.

Due to the differences in their functional level, clients at each level of the longitudinal system should have a unique group identity. Group identity is fundamental to integration. In addition to the establishment of the group identity of the cerebral palsied, integration also requires our clients to have a community presence and participation, obtained with support from the government through legislation and education of the general public.

### **Sociocultural Development**

Group identity of a population is established through sociocultural development. Active participation in a wide range of sociocultural activities that characterises a population contributes to the sociocultural development. Sociocultural activities refer to the whole range of human activities.

For ordinary children, sociocultural development can be regarded as a direct extension of natural maturational development. The maturational development refers to the development of skills for satisfying physiological needs, that is for maintaining life. Higher intellectual and psychosocial functionings are developed along the paths of sociocultural development. They arise out of collective behaviour, out of cooperation with surrounding people and from social experience. For the ordinary children, there exists an automatic transition from the maturational development to the sociocultural lines of development (Rieber and Carton, 1990).

On the other hand, cerebral palsied children face great difficulty in the transition from maturation development to sociocultural development. Since the entire global culture is designed for ordinary people, a suitable sociocultural environment for the cerebral palsied is lacking. As they grow up, their organic deficits give rise to divergence, discrepancy and disparity between their maturational development and the lines of sociocultural development within the existing global culture.

The habilitation system should endeavour to establish, within the global culture, a number of subcultures which provide suitable sociocultural environments together with a wide range of suitable activities for cerebral palsied with different functional levels. The boundary of the subculture is expanding as the clients climb the ladders of upward mobility. At the level of the independent home, the boundary of the corresponding subculture is the same as to that of the global culture. The establishment of these subcultures facilitate the cerebral palsied's transition from their maturational development to the sociocultural development.

### **Integrated Curriculum**

In climbing up the residential route from the large hostel, the population of the clients at each level display a pyramidal shape (figure 2). To facilitate upward mobility, integrated curricula have been implemented at all levels. These curricula link up the different levels of centres, aiming at promoting upward mobility and ensuring a smooth transition of clients from one level to the next.

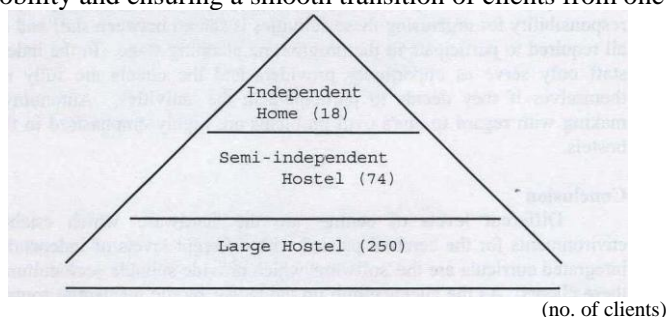


Figure 2 Population of clients at different levels of clients in the residential route of the longitudinal system.

The integrated curriculum serves to outline a boundary of the subculture for the clients at each individual level. In the residential service, the curriculum mainly covers 2 training areas, namely the domains of self-care and 'play'. Clients can utilise self care or play as a tool for improving their functional abilities or as an end for self-actualisation.

The curriculum is presented in an expandable syllabus, an operational manual for assessment and programme planning and a standardised set of documentation. It serves to link up different but related training programmes under a predetermined set of criteria outlined by the Petö's Concepts in order to cover a training area appropriately. The curriculum demands the adoption of a transdisciplinary approach, the provision of a holistic model of training and the establishment of a structured environment..

Under the transdisciplinary approach, barriers among different disciplines of staff are broken. Petö concept is adopted by the Association as the common philosophy which is shared by all staff irrespective of their professional background. Training programmes are found on the daily activities of the clients instead of the professional background of the staff. The holistic model of training refers to an integration of physical, cognitive, psychological and social training elements in the training programmes. The structured environment includes the establishment of a consistent and coherent atmosphere throughout the whole day of the clients, a tailor-made time table and specially designed physical settings.

Different curricula have been designed for the hostels at different levels. An individual lifestyle is founded on the self-care and 'play' skills. In the residential route, training in the self-care domain starts from personal self-care in the large hostels through instrumental self-care in the semi-

independent hostels to independent living in the independent home. Personal self-care refers mainly to the skills of daily living such as eating, toileting, bathing, etc. Instrumental self-care refers mainly to the domestic and the community living skills such as household chores, shopping, using public transport, etc. Independent living refers to an integration of all the self-care skills and knowledge in order to look after oneself and others.

Training in the play domain is another important part of the curriculum in the residential service. In the large hostels, staff take the role of programme organiser in providing games and sports for their clients. In the semi-independent hostels, the responsibility for organising these activities is shared between staff and clients who are all required to participate in the programme planning stage. In the independent home, staff only serve as opportunity providers and the clients are fully responsible for themselves if they decide to participate in the activities. Autonomy and decision making with regard to one's own problems are highly emphasised in the higher level hostels.

### **Conclusion**

Different levels of centres are the 'hardware' which establishes suitable environment for the cerebral palsied with different levels of independence while the integrated curricula are the 'software' which provide suitable sociocultural activities for these clients. As the clients climb up the ladder by the residential route, the degree of intervention from staff decreases. On the other hand, the degree of freedom clients and their responsibility for themselves are increasing.

The residential route of the longitudinal system represents an extended route which carries the cerebral palsied persons from their parental family to their own family. The integrated curricula serve to assist the cerebral palsied in striving for independence on their road to habilitation.

### **References**

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