

# SAHK

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## **Introduction**

Cerebral Palsy (CP) is a life-long functional disability which needs long term training. The habilitation of CP in Hong Kong normally starts from the diagnosis made. The Spastics Association of Hong Kong (SAHK) provides comprehensive services for cerebral palsied persons ranging from preschool service to adult service. When our clients reach 16 of age, three different routes of upward mobility are available for them to further practise integration (Fung and Su, 1995). These three routes are : (1) residential; (2) vocational; and (3) recreational routes (fig. 1). The ultimate goal of our habilitation is to facilitate people with CP to integrate into community as far as possible.

Integration does not necessarily imply the attainment of the highest level of the upward mobility. In fact, it can be achieved at any stage by any route according to the abilities of the clients (Fung and Su, 1995). For adolescents or adults whose brain damage occurred at a very young age, it is important to realize that their integration and development of self have not been completed, and thereby their personality development has been jeopardized (Ellis et al, 1980).

Motor and cognitive deficits together with the lack of environmental demand can result in a personality of 'learned helplessness'. The process of learned helplessness can be 'unlearned' if the disabled persons are taught to acquire strategies to control part of their environment and independently implement these strategies in different contexts of life. Development of such strategies cannot be achieved by tackling the client's problems separately by a multidisciplinary team of specialists, as human is a composition of interrelated structures functioned in a coherent whole. Thus, a comprehensive training which concerns the whole person is essential. A holistic model has been implemented in the SAHK for more than a decade and the outcome is promising. This paper presents of three cerebral palsied adults on their road to integration under our holistic model.

## **Integration**

Integration is defined as mutual understanding and respect of the identities among the general public and the CP population (Leung and Su, 1995). Instead of training the disabled to meet the standards of the abled, we focus on assisting the disabled to establish their own identity. Erikson (1968) stated that an understanding of the difference between what a person feels (experiencing-self) and what he or she observes (observing-self) is critical for the establishment of an integrated sense of self (identity). This understanding can be enhanced by the provision of external feedback and the use of behavioural technique. In our model, both the experiencing-self and the observing-self are upgraded through the process of image enhancement. Individuals with CP frequently are deprived of the usual opportunities that are appropriate for their age. In their life, they spend most of the time receiving treatment from the specialists, and all the while becoming more and more out of step with the rest of the community. By developing their underlying abilities to interact with the environment, and by encouraging them to have community participation, people with CP can

gradually build up their confidence, self-esteem and sense of belonging to the society. Their self and public image are thus being enhanced.

Gianutsos and Grynbaum (1983) suggested that by slightly altering the physical environment, the functional capacity of the brain damaged people can be increased. The use of specially designed physical settings and equipment should be regarded as part of the identity of the disabled. Thus, integration requires the provision of sufficient community facilities suitable for the disabled.

Finally, integration involves two parties. It cannot be realized without the active participation of the general public.

### **Holistic Model**

It has been mentioned earlier that by tackling the problems of a cerebral palsied client separately cannot assist the development of the problem-solving strategies and the establishment of identity which are fundamental for integration. The most critical concept of our philosophy is to view a person with CP as a 'whole' person in which altering in one component will have effect on the others. Thus a consistent attitude and holistic approach to training programs by all members of staff is warranted. In this holistic model, each therapeutic activity must consist of all the components underlying a functional problem. In such model, flexibility among specialists is needed so as to step out of one's professional role and to put the need of the client first.

### **Learning to be independent**

Mr. C is a wheelchair bound spastic ataxia with mild grade mental retardation. He was brought up in an overprotective family. No household chore was expected on him. Lack of environmental demand in daily life makes him poor in social as well as community living skills. More important, he lost his motivation to strive for a higher level of independence and showed reluctance to use the learnt skills in daily life.

To establish a consistent training for this client, family members must be involved. Regular home visits were made by social worker and/or occupational therapist. Family members were expected to know the client's potential and interact with the client the same way as staff. Parents gradually realized that their son had grown up and started to approach him with an age-appropriate manner.

Training for Mr. C was mainly directed at the community living and the household skills. At work, he participated in computer training. Mr. C was involved in the planning of his daily schedule in both the workshop and the hostel. According to his schedule, he was assigned to do the cleansing work after meals and to pay regular visits to a nearby youth centre.

Positive reinforcement was used at the beginning aiming at overcoming his motivational problems. He was appointed as the leader of a small group. He was also asked to give announcement during morning assembly. By giving him freedom to make decisions and opportunities to assume responsibilities, he became more motivated to learn. His performance was videotaped so as to give him feedback on his progress.

Mr. C was reluctant to use rhythmical intention (RI) for learning new skills. Activities facilitating gradual acceptance of RI was planned. Mental practice is the visual imagination of the movement performance while labelling is the naming of the movement components. At the beginning, only mental practice was introduced to him. Verbal expression was eventually used spontaneously by the client especially when tackling complicated tasks. During gait training, Mr. C used the 'intention' component of RI as labelling of the movement sequence of walking and the 'rhythm' component for monitoring the walking pace. He is now able to walk in the centre with a rollator with only standby assistance.

After one year of training, Mr. C was discharged from the hostel and moved up to an independent home. Now, he shares a flat with a cerebral palsied roommate in the independent home. They are required to share between themselves all the household work including shopping. Although Mr. C has little potential for open employment, he finds his way of integration through the residential route.

### **A strive for an improvement**

Ms F graduated from a school for the severe grade mentally retarded. She received continuous physiotherapy and occupational therapy for more than ten years. She was totally dependent in self care and was reported to have no hope for further improvement. She withdrew from her surroundings and showed poor response to external stimuli.

In the sheltered workshop, she was placed in a carefully selected homogeneous group in which she could identify peers for modeling and for competition. Initially, she idled in workshop most of the time and showed little awareness to her surroundings. Since higher psychological processes are social in origin, 'awareness' develops as a result of people's social experiences (Luria, 1966). Intensive feedback on her performance was provided both from the staff and from her peers. She was also made to be aware of the improvement achieved by the other group members.

Her physical abilities only allowed her to perform simple and repetitive tasks. By means of task analysis, the packaging work was broken down into a number of small components. At the same time, she received intensive training in spatial orientation and in gross hand functioning during the group training sessions. With careful guidance by the trade instructor, Ms F was eventually able to find out one component of the packaging work that she could participate: transferring the working materials to her partners. The group members and staff showed their appreciation to her and the identification of her role at work highly motivated her. This further stimulated her awareness to the surroundings.

Once she had found her role in the production line, she experienced her significance and contributions to the workshop. This small success induced her to participate further in the training activities. She became more active and cooperative. She is now able to feed herself and propel her wheelchair independently, though slowly. Ms F is an example of integration started in the vocational route and generalised to the residential route.

### **Another blossom of continuous effort**

Ms N was diagnosed as a severe grade mentally retarded athetoid lady. She received no formal treatment and training before joining our Association. Her sitting posture was poor. Her shoulders were retracted, making her unable to use her hands for manipulation. She was totally dependent in self care and she drank water by sucking from a milk bottle. A learned helplessness personality was adopted by her, and she refused to cooperate in the therapeutic activities.

To motivate a client with limited mentality, therapeutic activities should be focused on her physiological needs. To improve her sitting posture, we moved her out of the wheelchair and sat her on a stool during her leisure time. To avoid falling, she had to reach her hands out and grasp onto a bar in front. By reaching out, her shoulders were protracted. Our training was then directed at improving her upper limb functioning. The ability of shoulder protraction was generalised from the leisure time to the meal time. At the beginning, she was fed by the staff. Then she was requested to wipe her mouth with a towel after meal. Since she was highly motivated by sweet food, after-meal dessert was used as reinforcer to encourage her to grasp a spoon. After seven years of training, she is now able to feed herself with a spoon at meal time with little assistance.

As her upper limb functioning was improved, we attempted to train her to drink with a double-handled mug. However, the client refused to try. In the interdisciplinary case meeting, a welfare worker reported that Ms. N had shown interest in joining the horticulture club in hostel. The therapist then made a deal with her by requesting her to water the plant with the double-handled mug. The blossoming of flowers motivated her further and she learned quickly in manipulating the mug. The involved welfare worker then gradually encouraged the client to generalise the skills from plant watering to drinking. This is an example of integration started in the recreational route and continued in the residential route.

## Conclusion

The fundamental element of integration is identity establishment. In our model, we assist a person with CP to establish his or her identity through the process of image enhancement. Image enhancement requires the development of the problem-solving abilities together with community presence and community participation.

To realize integration, a holistic model is warranted. The holistic model involves a transdisciplinary habilitation team which views its cerebral palsied clients as a 'whole' person. Therapeutic activities encourage cerebral palsied clients to adopt functional problem-solving strategies. In turn, clients must take an active role in their training programs and not just wait for the habilitation team to make them better. Lastly, but not the least, active participation of the general public is indispensable for assisting the integration of CPs into community.

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