

PSYCHIATRY OF LEARNING DISABILITY — A TIME TO SOW, A TIME TO GROW

THE TIME TO GROW

The mental health service is very often the last specialty to be developed in many countries, specialist services for the learning disabled is often the last psychiatric subspecialty to be established. There is doubt and controversy about psychiatrists' roles in the learning disability services and Hong Kong is perhaps no exception.

There is a time to sow and a time to grow. Is it the right time to review the development of psychiatry of learning disability in Hong Kong? Many movements and changes tell me so. The Social Welfare Department is currently undertaking a comprehensive review of the residential needs and service provision for people with mental and physical handicap. The Mental Handicap Working Group of the Hospital Authority has been active in arranging not only commissioned training on learning disability by overseas experts but also local training programmes on art and music therapy. Maybe the wind is blowing strongly in the right direction at last. But which way to go?

THE UK MODEL

Due to historical reasons, the local psychiatric services have been similar to those in the UK. Naturally, we have studied the UK service model while considering our own. Perini reviewed the history of development of the management of learning disabilities in the UK and commented that they are now well into the post-hospital/post-institutional era with most people with learning disabilities being cared for in the community.¹ Within the UK mental health services for people with learning disabilities, there has been further specialisation and development in psychiatric services for people with learning disability such as:

- networks of local integrated services consisting of specialist inpatient units in partnership with a community learning disabilities team²
- psychiatric services for children and adolescents with learning disabilities³
- forensic services
- psychotherapy and family therapy.⁴

Nursing the learning disabled population has also undergone inevitable changes in the past few decades.⁵

THE LOCAL SCENE

Currently, Hong Kong is still lacking a consultant-led full-spectrum psychiatric service for learning disability. The majority of people with learning disability are under the care of the generic psychiatric services and are at an obvious disadvantage in comparison with people with mental illness alone. Their need for a specialised service remains unrecognised. People with learning disabilities and their families suffer from the lack of appropriate mental health services. Their disability and handicap are heightened by a reluctance to attend generic psychiatric services and the consequential delay to and non-compliance with treatment.

Kwok argued convincingly and with ample evidence that there are valid reasons for the recognition of the special needs of people with learning disabilities and mental illness and the establishment of the psychiatry of learning disabilities as a subspecialty in Hong Kong.⁶ He further recommended a hospital-based system with multidisciplinary input and strong community connections.

NORMALISATION AND LEGISLATION

Normalisation and integration has been argued as a defence for why people with learning disability should not be segregated or separated from other mental health service users. Some psychiatrists believe that people with learning disability would have obtained sufficient care from the generic psychiatric services. However, community groups (particularly relatives of learning disabled people) have expressed their wish for a separate mental health service for learning disabled people. These community groups have objected to the inclusion of mental handicap into the category of 'mental disorder' in the Mental Health Ordinance as amended in 1988.⁷ 'Guardianship' was criticised as emphasising supervision and control, rather than care provision. The needs of adult mentally handicapped persons have been repeatedly referred to by community groups and the media. Specific issues relating to consent and authorisation of carers have been discussed. Successful negotiation between these community groups with Legislative Council members and government officials resulted in the re-amendment of the ordinance in 1996. The amendment has been passed by the Legislative Council and the amended ordinance was implemented in February 1998 with the establishment of the Guardianship Board.

As explained by Hung, the introduction of a new category of 'mental incapacity' — defined as 'mental disorder or mental handicap' in the Mental Health (Amendment) Ordinance 1997 — may or may not have made a dramatic impact in the sense of revolutionising the day-to-day service provision to people with learning disability.⁸ However, it is thought to be helpful for ascertaining the controversial issues and grey areas in care provision. But is it? As revealed in the statistics from the Guardianship Board, of the 82 guardianship orders issued in the year 1999 to 2000, only 11 patients (13%) had a disability arising from mental handicap in comparison to 33% with Alzheimer's dementia, 17% with mental illness, 13% with vascular dementia, 13% with stroke, and 10% with brain injury.⁹ Hence, not many cases of learning disability are benefiting from the use of the new amendment. Normalisation and social role valorisation (SRV) are widely acknowledged to have strongly influenced reforms to services for people with learning disabilities in many parts of the world.¹⁰ Social role valorisation is a social theory with relevance to a wider group of people who experience social devaluation. The theory is based on an account of the common experiences (wounds) of devalued people and the development of 10 bodies of conceptual and empirical knowledge (themes) that provide explanation for social devaluation and generate strategies to counter it.

Knowing it, talking about it, and teaching or preaching it may be very different from putting it into our daily practice. Earlier this year, the Department of Social Work and Social Administration of the University of Hong Kong held a series of thought-provoking workshops on *A Systems Approach to Normalisation in Social Services for Persons with Mental Handicap*, with participation from many learning disability service providers. The concept of normalisation may need to be revisited, with emphasis on the accurate recognition and acceptance of the special and individual needs and strengths of each person with learning disability and the realignment of the expectation and boundaries of the different systems (namely self,

family, schools/hostels, medical services, other service providers, and the public) providing care and services to them. It is not enough to 'pretend' that people with learning disability are 'normal', be blind to their special needs, treat them with other service users, and call that 'integration'. The gold standard for any application of normalisation will be the enhancement and enrichment visible in the quality of life of people with learning disabilities. There should be no other benchmark than this.

The tide is changing and the outcry in society is getting louder every day. I believe that this is just the beginning.

REFERENCES

1. Perini AF. Development of health service policy for people with learning disability in the United Kingdom. *HK J Psychiatry* 2000;10(4):18-21.
2. O'Brien G, Radley J, Joyce J. Adult learning disability psychiatry services: local implementation of national guidelines. *HK J Psychiatry* 2000;10(4):22-24.
3. Berney T. Psychiatric services for children and adolescents with learning disabilities. *HK J Psychiatry* 2001;11(1):17-20.
4. Hollins S. Developmental psychiatry — insights from learning disability. *Br J Psychiatry* 2000;177:201-206.
5. Minto C. Contemporary issues in learning disability nursing — a UK perspective. *HK J Psychiatry* 2001;11(1):25-28.
6. Kwok HWM. The provision of specialized psychiatric services for people with learning disability (mental retardation) in Hong Kong. *HK J Psychiatry* 2001;11(1):21-24.
7. Chang W. Inspirations obtained by self-help organizations in the process of promoting the Mental Health Amendment Bill 1997. The Hong Kong Joint Council of Parents of the Mentally Handicapped; 1997.
8. Hung CHR. Mental handicap and Mental Health (Amendment) Ordinance 1997. *HK J Psychiatry* 2000;10(4):15-17.
9. HKSAR Guardianship Board. Guardianship Board First Report February 1999 — January 2001. HKSAR Guardianship Board; 2001. In press.
10. Cocks, E. Normalisation and social role valorisation: guidance for human service development. *HK J Psychiatry* 2001;11(1):12-16.

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