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EDITORIAL

There is a widespread naïve belief that settling a m.h. person into a home situated in the open community will automatically avoid the handicaps caused by a closed community — the institution. It is thought that such a resettlement is THE decisive step, the first step, so to speak to derive benefit from the freedom of the open community and also the last step necessary for the m.h. to achieve the dignity of being able to live the life of the majority of people. There is a strong tendency by all concerned to turn to other business after having achieved the dramatic reversal of a historic development by reallocating resources from institutions to local communities, by agreeing to run down, to reduce and finally to eliminate institutional provisions, by appointing new staff and emphasizing non-institutional management practices. Yet, one may well wonder whether the new landscape that will evolve out of the shake-up will not be the old one which has simply shifted its location like the dunes of the Sahara after a sandstorm — but the barrenness of the desert still unchanged.

Whether one regards such effort on behalf of the m.h. as a first step of opening the door to the community or as the last step of a community having agreed to open its door, it is decidedly not enough in itself because it is likely to end in most cases in a vegetating existence in new surroundings and causing in many other cases bewilderment, disturbance, anxiety and isolation. It is really a step somewhere in the middle which must occur only after a preparatory course of deinstitutionalizing measures and which must be followed up by an adequate system of individualized measures designed to tap fully the so far unexplored personal resources of the m.h. for living a fuller life. One must not expect that learning academic, domestic and manual skills, or having opportunities for easy access to the open community can be fully exploited by people to whose impairments society has added the additional handicaps of making decisions on their behalf right from the beginning. Our natural inclination to assist them continually and the steps taken to ensure effective help lead to personality deficiencies in people who are thereby made aware of their shortcomings, who are constantly supervised and observed, who are dependent on the goodwill of others and who feel ill at ease in unfamiliar surroundings. They share these feelings with many 'normal' people but in their case it would be wrong not to deliberately strive towards a reduction of disabling feelings of diffidence, insecurity and inferiority simply because we assume that a new life will automatically bring about a reversal of personality development of long standing.

The Symposium in this issue on "The Way into the Community" is probably quite a representative sample of various highlights of present-day strategy and endeavour, showing what is being done — sometimes, and even more important what is not being done.

The first article from Scotland directs attention to the need for increasing the provisions for m.h. people to a much larger degree than the official figures propose. This will affect not merely residential accommodation but will also require more Adult Training Centres and sheltered employment. Judging by present-day standards, such developments will result

in the resurrection of very well managed Occupational Centres with an industrial camouflage which pay only lip service to habilitation work and the developmental growth of the m.h. adult. But comprehensive habilitation work is essential because, for example a substantial proportion of m.h. people living with their relatives now will, eventually become the responsibility of the authorities and, as the authors point out, a m.h. person 'after many years of dependence on his parents will not be able to cope with independent living'.

The second article from the Mental Handicap Team in Wales discusses the unevenness of distribution of m.h. people with varying degrees of dependency. Whatever the reasons for the unevenness the fact remains that the majority is considered to fall into 'two main categories "can and able" and "medium dependency"', which suggests that there are many people who could achieve a higher standard of independence than that which is required for being passively shunted from and to ATCs and grouphomes.

The last two articles deal with some of the work done to make the m.h. more capable. Some hospitals have attempted to free themselves from the pernicious burden of institutionalism and have accepted that their work incorporates a preparatory training stage before m.h. people join the open community. Predischarge Units, Social Education Centres and suchlike have been set up where various domestic and self-help skills are taught belatedly in artificial situations. But even separate homelike residential accommodation provided within institution grounds does not escape the institutional régime as is pointed out in the third article, and misses thereby utilizing those very opportunities of ordinary home life which would enlarge the m.h.'s social competence. If this régime is, additionally, also subject to medical requirements with legal consequences for doctors and nurses, then its effectiveness in helping handicapped people to grow socially and personally becomes very limited. The very fact that in this setting they are 'patients' who have been placed there for their protection, makes it impossible to guide them towards the final aim of shouldering responsibility because during this process risks will have to be taken. There is a grey zone of uncertainty when the regulations and even the law appear to contradict the demands of educational commonsense, and nurses and doctors have to set aside thoughts of protecting the 'patient' in the interest of developing the person. Letting him run a bath and cleaning himself in privacy, giving him opportunities to tackle busy street traffic, exposing her to the risk of pregnancy, entrusting him with his own medication, letting her choose her own friends, letting him sleep unsupervised and unobserved — these are all steps towards a more normal life which have to be gradually learned and individually faced up to — but they are considered 'risks' in a hospital setting. Where opportunities for learning are seen as risks and can therefore not be introduced when required, the educational work of the institution has effectively not moved away from the days of Itard and Seguin when teaching of self-help, academic, domestic and manual skills was carried out with much mistaken optimism.

If the hospital is unable to provide their 'patients' with more than a smattering of rudimentary skills, who then has the task, the obligation, the moral duty of stressing the additional dimension of social competence which means that m.h. people learn to make responsible decisions *without having to be prompted?* The honest answer is NO ONE. The wardens or 'officers in charge'(!) of residential units see it as their task to provide comfortable happy and supportive hotel accommodation — not to act as midwives to wobbly attempts to assert oneself. The managers(!) of ATCs provide, but for a few notable and isolated exceptions, industrial and craft occupations and organize for a few people social education classes at the centres and attendances at Further Education Colleges. These praiseworthy efforts of making the illiterate literate are necessary foundation stones but there is nowhere any evidence that a building will be erected on them which is designed to help the m.h. in developing responsible self-confidence and his capabilities as a person — not only as a worker.

The final article relates the efforts made to insert some orientation and direction into the routine of an ATC. Only a little time was set aside for striving towards specified goals.

There is evidence that the method adopted is successful and can achieve measurable results. It is not unrealistic to assume that a planned approach could deal with many aspects neglected at present. Successes of this kind are however entirely due to a fortuitous set of circumstances such as interested management, willing staff and a diplomatic psychologist. There is no obligation specifying that time and resources must be set aside for structured work which will meet the assessed needs of the individual. As long as the educational and developmental role of the ATC is not spelt out in unmistakable terms and made the raison d'être for its existence, the m.h. will remain at a low level of personal functioning and the ATC will function merely as an occupational facility.

If we neglect awakening latent capabilities from early age, removing interferences from outside or nurturing capabilities through a prolonged stage of maturation, we shall fail in reducing the numbers of people dependent on others, and, on the contrary, increase not only their numbers, but also the numbers of those who have to care for them. There is, at present, no paramount obligation, no real commitment to develop the person, and not only the skills of the m.h. There is still no conviction that such a person could do more for himself — there is only a desire to do more for him.

Point of View

IS HANDICAP EXTERNAL TO THE PERSON AND THEREFORE 'MAN MADE'?

Perhaps the word 'handicap', has, for too long been confused with the words 'impairment and disability'. It is clear from the literature that the definition 'Mental Handicap' is indeed a factor for multi-disciplinary confusion. This confusion becomes apparent when administrative structures impact on or contradict each other due to different professional or semantic interpretations of handicap.

The International Classification of Impairments, Disabilities and Handicap (WHO, 1980) illustrates this fundamental point. It defines an *impairment* as any loss or abnormality of psychological, physiological or anatomical structure or function. A *disability* is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being. Whereas a *handicap* is a disadvantage for a given individual, resulting from an impairment or a disability that limits or prevents the fulfillment of a role that is normal depending on age, sex, social and cultural factors for that individual.

Many mentally retarded people would suffer from several entries on these classified lists. It does, however, illustrate how much both the literature and the administrative structures that exist are geared to the impairment or even the disability, but so rarely to the handicap.

Do emotional factors such as feelings of inadequacy, self image, unsatisfactory adjustment and feelings of non-acceptance require concentration on a medical condition, or do these factors warrant public education, person centred administrative structures and more personal control and involvement in decisions affecting ones own life?

Included in the classification of handicap categories is social integration, handicap and occupational handicap. The relatively large number of actions listed that are external to the impairment and even to the disability demonstrate that handicap is largely external to the person and possibly 'man made' due to (inappropriate) administrative structures. Are we concentrating on the disability to the detriment of the more curable aspects of handicap e.g. prejudice, lack of freedom, etc.?