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EDITORIAL

Facts produced by recent research tend to induce a certain degree of sobering down after the excitement of opening institutional gates and setting the scene for community integration.

Our leading article (Sumpton et al, see p3) picks out a group of m.h. people who missed the boat during those last few years when changes happened to everyone else but not to them. How representative this group is of a proportion of people who will still be institutionalized in years to come, is difficult to say. No doubt, claims on community homes by people who have to leave their parental homes will compete with the claims of people still in institutions and will affect seriously their chances. As the article concludes, "change in the direction of care in the community will have to be a very great change" for the hard core not transferred yet.

The dispersion of small groups of very dependent people to live in ordinary homely rather than hospital/institutional environments is obviously preferable from their point of view and from that of their relations (see S. Halliday, p 3) and it may well release unused abilities (see W. R. Dunlap, p 66), which had not been able to develop in adverse circumstances. One becomes, however, also aware of the expense of such units if a **higher quality of service than hitherto is to be given and maintained**. For example (see G. Evans et al, p 10) ordinary housing for 5 m.h. residents may require a team of ten people, and even, if one considers that developmental training may well reduce the dependency of many handicapped people, and more economical ways of staffing may be devised, it is obvious that an acceptable staff:resident ratio will always provide major headaches for all concerned. One must also be aware that the conscientious application of guiding principles to the service, the insistence on social training schemes, the attempt to change attitudes, etc. are still based more on faith and common sense than on convincing evidence that m.h. people can be successfully eased into the community **because** of sophisticated programmes (see Humphreys & Blunden, p 19). Sooner or later, when other demands are made on finance, organisation and manpower, less sympathetic questioning will become more searching and any arrangements exceeding the obvious and decent caring obligations towards weak members of the community, will have to be passionately defended with sound facts.

Once the material and physical support which society as a whole is prepared to marshal and to pay for has been properly organised and weaknesses in the systems have been overcome (see A. Corden, p 57, Halliday & Potts, p 31), the m.h. person will join the large groups of the needy, the old, the sick, who are being regarded as full members of that society — in theory at least. As we all know, these groups have still to fight for their rights and even more for their acceptance

in an egotistical and essentially disinterested society. The m.h. is not easily accepted, not as a child (see Gilkey & Zetlin, p 50), even less as an adult and a pessimistic scenario may well come to the conclusion that our tremendous efforts changed the scene only from institutional custodialism to a kind of integrated community custodialism, where no one can say any longer "out of sight, out of mind", but where also no one can guarantee that "within sight" now will also mean "within mind" tomorrow.

This issue of the BJMS reflects one aspect of deinstitutionalization, namely the preoccupation with the concrete consequences of exchanging one set of physical factors for another. M.h. people are now about to receive a share of the minimum of creature comforts which society as a whole owes to its weakest and least vocally demanding members. Whether individual members of that same society are prepared to come forward and extend generally a helping hand, to establish a warm, sympathetic human contact, to make a kind remark in passing and, on a slightly higher level, the short impromptu conversational gambit, the enquiry, the considerate support, is perhaps doubtful. Spontaneous human contact is becoming a scarcity with the old, the sick and the disabled, and why should the m.h. — now part of the same group — receive a share that may well have to be larger than that of other people? It is, after all, unquestionable that he, because of the nature of his handicap, has little capacity to compensate for his loneliness, isolation, unhappiness, fear and insecurity and will therefore require a greater share of affection and attention than other handicapped people.

To some small extent a dosage of assured daily human contact is, of course, still provided by the staff of grouphomes though this rather limited and cramping environment may, despite all efforts not be able to counteract the disinterest and rebuff endured by the m.h. in the open community. Casual positive encounters — the smile, the greeting, — occur less and less when shopping, taking a stroll, sitting in the park, yet they are an emotional stimulant which is vital for the unsure and timid. The uncaring attitude of most of the public towards individuals will not be easily changed. The organising of "friends", of club visits, of holidays and outings, of entertainments, etc. are necessary but not quite satisfactory substitutes for normally occurring individual contacts. Everyone likes "his" friends, "his" family, "his" own personal memories, etc. and unless we are able to do something about this aspect, the m.h. will not be as happy and settled in his new "home" as he needs to be. An absence of these "normal" facets of "normal" life may well be the price that has to be paid for better individualised living conditions in the community and the freedom of living a life of comparative independence. Those of the m.h. people, who are the pride and joy of successful training programmes because they can live on their own without constant supervision and help, could be the people paying the highest price — an increased degree of isolation and even segregation — but others too, in their small grouphomes will most likely pay a similar price.

This other aspect of deinstitutionalization, the effects on unassertive people placed in an egotistical society, is neglected by research and discussion, but is nevertheless of vital importance for evaluating the true impact of our present policy. Here in this area could be hidden the greatest pernicious side-effect of the radical treatment prescribed by society to avoid the consequences of institutionalism. It would be quite wrong to overlook possible negative effects of our policies in our joy of creating such healthy conditions for growth and development. We must develop means to eliminate these side-effects. Otherwise we may well have to apply some day another radical treatment to stop the deleterious effects of integrated community custodialism.