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EDITORIAL

The adequate settlement in the open community of some 125,000 m.h. adults here in the UK is obviously a tremendous task and presents an ongoing care obligation. Similar numbers will have to be cared for by future generations. Nothing at present suggests that we shall be able to decrease the number of people with a mental handicap substantially in the near future. On the contrary, better living conditions, improved medical treatment and care are said to increase the numbers of dependent people, simply because they live longer than in the past. We are confronted with a permanent responsibility which can be faced by many carers only - not by all - if they can see some progress possible as the result of their efforts. If that success can be shown in terms of greater independence of people who were thought to be incapable of it, this success will not only provide motivation for those who care and train, but it will also reduce to some extent the otherwise increasing burden on society.

.....That people with a severe mental handicap will always be in need of continuous assistance by social welfare agencies, just as indeed thousands of people with other kinds of handicaps, is accepted in a civilised society without a murmur. Yet, as in the case of humanitarian assistance given to developing countries, where the question is asked whether the form of help given is necessarily the most effective one we may well ask the same question in the field of mental handicap. Are we simply perpetuating and thereby unnoticeably increasing dependency by viewing mental handicap mainly as a care problem? Should it not be possible to increase substantially that minority of people who can help themselves to some extent, despite this handicap and therefore require less resource input?

Many reports available nowadays describe the lives of people with a mental handicap who - with help from the social services - have settled in their own homes and live a "normal" life. This is the equivalent to overcoming a physical severe disability by giving the person the means to look after himself to his own satisfaction even though he still requires support.

It is likely that only a small minority is capable of achieving this degree of independence, but how small is small? If one were to accept for example the figures of the North West Thames RHA register*) as an approximate indicator of the situation in the whole country possibly no more than 3 percent of people with a mental handicap are housed in their own flats and living quarters and could therefore be regarded as genuinely having been discharged from custodial care even if the helping hand must always be readily available. Three percent is a suspiciously small figure and may not indicate the total number of people who could live in this way. The low percentage simply points to the proportion of resources which, it has been decided, could be set aside for this particular purpose of housing on their own. It is not related to the number of those who are potentially capable of living with less assistance than is given to them in grouphomes, hostels, etc. The low number of accommodation for semi-independent living suggests a continuation of custodial policy despite the fact that large institutions have been replaced by a multitude of small grouphomes, hostels, nursing accommodation, etc. dispersed in the community. The only exit from this community-custodialisation is via the far too limited number of accommodation for semi-independent living. The shortage of this type of accommodation is also closely related to the absence of effective habilitation methods which would help m.h. people to look after themselves to some extent. It is unacceptable that absence of these particular provisions should be defended and explained by making statements that not enough suitable people were available. Only when m.h. people have gone through forms of training which have been shown to be effective, and have still not acquired a modicum of self help and social skills and must therefore live in "custodial" conditions, can we feel reasonably sure that shortage of such provisions does no longer contribute to our inability to reduce the growth of numbers of dependent people. Considering how often m.h. individuals have surprised professionals with unexpected attainments, giving only three percent of the m.h. population an opportunity to attain a higher level of self sufficiency is another example of shortsighted and incompetent planning which fails to utilise fully the opportunities deinstitutionalisation has brought with it. Wolf Wolfensberger, the apostle of "Normalisation" has put it very strongly: "The kind of habilitation and program-supported community living that some of us had envisioned in the early days of the reform movement has been grossly perverted and sabotaged"***.

It is, of course, appreciated that living a semi-independent life requires substantial preparatory training before people with a mental handicap could make use of the opportunities now opening up before them. This training has to be given by professionals who know that their trainees are not only people with learning disabilities

* R. Farmer, J. Rohde and B. Sacks, Dimensions of Mental Handicap.

** W. Wolfensberger, Reflections on a Lifetime in Human Services and Mental Retardation. *Mental Retardation*, 29, 1, 1-15.

and learning difficulties but have also mental disabilities, which affect decisively their personalities and colour their reactions to the world around them. This has to be taken into account when designing social/educational programmes, training social skills and preparing people for living in less protective environments. The development of more efficient and widely applicable methods, the evaluation of results achieved, need the professional dedication and common sense of people who are fully familiar with the implications caused by the presence of mental disabilities. They must be prepared to devote an appreciable slice of their working life to a long, time and energy consuming search for practical habilitation approaches which can be used with people who have personality problems besides learning problems.

Establishing a multitude of varied accommodation for semi-independent living must go hand in hand with intensive specialised research effort into habilitation work preparing for this type of living. This will be of direct benefit to many of the present generation of m.h. people who otherwise will continue to be cared for in small community institutions and it will also avoid subjecting coming generations to a repetition of frustrating "treatment" approaches which have only moderately been successful.

It is disquietening that among all the plans and proposals put forward to outline future services for the mentally handicapped there is much stress on individual assessment, individual programmes, individual reviews, etc. and references to staff training, recreation and vocational activities etc. but no demand for arranging time, resources and manpower to explore and research novel and more effective ways of enhancing the abilities of m.h. people which, one knows, are there in a dormant state. It looks on the face of it, that everyone concerned is quite sure that everything there is to know, has already been discovered and has become an established and proven body of knowledge, that it is simply a question of spreading the good news, make more people aware of it, make people apply it, create the most favourable conditions and everything will turn out just fine.

It is true, that much knowledge has accumulated, but this provides only the buildingblocks for a very fragile and rickety scaffolding of expertise which has not yet been widely applied, tested and consolidated and does not offer firm enough a platform for general use. Relying on fumbling hopefully about and not even being able to take proper advantage from trial and error is wasteful, disheartening and bound to end in a pessimistic standstill. If one wants to enlarge these three percent of habilitated people, it needs not only more of the right type of accommodation for semi-independent living but also the research teams to find better and more successful ways for achieving results. Increasing the three percent to five, to ten or more percent can not be achieved by relying on the lukewarm application of half-digested methodology, but requires intensive research effort by people immersed in the problems of mental handicap with all its repercussions. Our problems are unlikely to be solved by selecting and isolating "interesting topics for research" in the areas of learning

disability or learning difficulty unless we also devote attention to the context of the mental disabilities in which they occur.

It is, perhaps, an unavoidable sequence to the disappearance of a clearly described and concretised speciality with its hospitals, nurses, doctors, professionals, who were considered experts in this particular field (probably with justification only in a few cases) that the so desirable diaspora into the open community has also resulted in a reduction of very obvious opportunities for systematic research work - even though these were, alas! too often overlooked and neglected in the past. Yet the new scene has not brought about a noticeably better situation as far as intensive cooperative effort between research and practice is concerned. The present transition phase which decreases day by day the status and importance of specialisation but emphasises the generic point of view where mental handicap is only one of many problems has diminished research efforts of substance. Psychologists working in the mental handicap field, who in the past were leading in exploring and discovering new approaches and techniques in their chosen speciality let themselves be diverted by the new managerial and administrative tasks which have become available to them but which, necessary as they are for creating favourable developmental conditions, leave no time for prolonged research effort.

The research input comes now from outside the field, from universities and polytechnics where professionals prefer the small scale investigation, requiring comparatively little time and no commitment to extended labour intensive work. Research into mental handicap aspects seems nowadays often to be done mostly by people in search of a paper to be published, for which data can be collected on three or four visits and who turn their attention very soon to other aspects of community care. One misses research which has been initiated by the "doers" and guided and evaluated by those with the necessary scientific knowledge. The emphasis has now shifted to researches which obtain their data from questionnaires and interviews, the themes concern attitudes of public, staff and clients, and "experiments" are seldom adequately followed up for more than three weeks after completion of the investigation. Researchers deal no longer with people called children, men and women, Tom and Jean, but with subjects, called males, females, client No. 12 or Caucasians. They report the scores obtained by a subject and the significance of results, but fail to consider the impact of the experiment on the m.h. people themselves, who may have been taught skills to their delight which are completely disregarded by others as soon as the psychological circus has left town. Necessary as these investigations may be, one misses not only the facts and findings being pursued, elaborated, tested and applied in daily practice and independently taken up by other researchers, but an appreciation that the "experiment" resulted not only in an increase of scientific knowledge but concerned also human beings and added to their welfare. It is only too obvious, that many a researcher has no time for building up a knowledge of experimental work and of human relationships and is unable or unwilling to see how much

results and methodologies are influenced by "human" factors which he fails to take into consideration and which ought at least to be commented on for the sake of those colleagues who want to make use of his work. One misses particularly that type of research where the reader feels that the investigator knows more about the people he has been working with than he reports in tables, graphs and figures. How could he indeed, having spent only five minutes with them!!

Having drafted above paragraphs the writer found unexpected confirmation of his unease regarding the professional contribution to habilitative mental handicap work when belatedly reading an Editorial in the Journal of the American Association on Mental Retardation. The relevant comments deserve extensive reporting:

"The great majority of the workers in the mental retardation field lack the commitment to move the field forward . . . Because of the short-term involvement in mental retardation, the continuity of the field is disrupted. The number of researchers in mental retardation has declined in the 1980s . . . A number of our research leaders feel burned out by the constant need to fight for scarce research dollars. The younger researchers have not tended to join the battles. We need to find our next generation of research leaders. . . . We must have a mission and a vision for the future . . . We must train the next generation of professionals in the field." ***

The question to be asked is: Does this analysis only apply to the American situation?

*** L. Rowitz, (Editorial) Leadership in Mental Retardation, *Mental Retardation*, 1991, 29, 3, III-IV.