



EASTERN NEBRASKA

HUMAN SERVICES AGENCY

INTER-AGENCY MEMO

TO: Area/Division Directors

FROM: Warren Spencer & Shirley Dean

DATE: June 23, 1981

REGARDING: Tyne/Williams Critique

Attached is a critique of ENCOR services compiled by Alan Tyne and Paul Williams during their recent visit. Please share it with your staff, since many of them were involved with these two visitors.

Over the last nine or ten years, a steady stream of visitors have come from England to Omaha, specifically to see the work of ENCOR. Mostly the visitors themselves work in services for mentally handicapped people, and many of them belong to a network of colleagues and friends in the United Kingdom known as the "Campaign for Mentally Handicapped People" (CMH). After visiting in 1978 and 1979, Alan Tyne and Paul Williams called together in London a group of some ten people all of whom were familiar at first hand with ENCOR's service. With support from the King's Fund Center (a major national center with interests in Health Service Administration, as well as in developing community-based service for people needing "Long Term Care", including elderly, physically handicapped people, and those with problems of mental handicap or mental illnesses) a working group met frequently over a year. The group wrote a detailed account of ENCOR's residential programs and then analyzed ways in which comparable services could be developed in the context of English Health and Social Services Administration and funding patterns. Their report has been published by the King's Fund under the title "An Ordinary Life".

In our experience, which includes knowledge of Scandinavian services as well as those in many American states, ENCOR's services are unique. All of us are aware of limitations, indeed severe problem areas in ENCOR's service - provision. Nevertheless, we believe ENCOR is a most valuable model of comprehensiveness, of ideological commitment, and of high quality service delivery. In the United Kingdom, we have many examples of good practice but nowhere are all the elements of a service system combined in the way they are in ENCOR. Although increasingly our policy makers adopt a rhetoric of "community-based services", people have often very limited understanding of the kinds of community services which are possible. Thus "community" provision is currently taken to mean 24-bed hostels offering places only to the most capable and independent of mentally retarded people. Day services are usually 120 place programs on a "mixed model" of work training, social education and diversionary activities. Some 50,000 adults (1 per 1,000 of the general population) continue to live in long stay hospitals, and although the number is reducing, new hospitals of 100 or so beds are still being built at huge cost. Hospital based professionals increasingly strive to provide "out reach" services in the community, and there is a growing emphasis on developing multi-purpose resource centers (called "community units") to provide most routine services to mentally handicapped people, but still relying on hospital "back up" for clients with more complex needs.

CMH and the Ordinary Life working group are profoundly dissatisfied with both the pace and direction of these service developments in the United Kingdom, and through the CMH's Education and Research Association, have established a program of training, workshops and seminars as well as planning consultancy. CMH's presentation and workshops have held up ENCOR as a model. ENCOR materials and publications, and a set of slides made in 1978 have been extensively used (Alan Tyne says he has showed his ENCOR slides upwards of 80 times now, all over the United Kingdom). The result is that some substantial and many minor projects are under way all over the United Kingdom, developing the use of ordinary housing, exploring new vocational and educational options and looking at ways of helping some severely handicapped people to share in community living. A major consultancy exercise with the Guy's Health District, a health authority in central London, has produced an exciting plan for a comprehensive community-based service modeled closely on ENCOR. The ENCOR model has stimulated wide interest - and even some action!

Needless to say, there has also been strong opposition. Although in the main our use of the ENCOR model has made people more aware of some of the possibilities for community integration, there is a failure to understand the important philosophical issues. Our own work in developing normalization and "PASS" training in the United Kingdom is beginning to address this problem. More specifically we encounter fierce professional opposition (especially from medical and psychiatric "experts", but also from social workers and others) which insists that "there will always be those whom only the hospital can serve". This is despite overwhelming evidence that the people with the most severe handicaps or behavior problems are likely to be most grossly neglected and abused in our "hospitals" for mentally handicapped people. In particular we are firmly told that people with multiple handicaps or severe behavior problems cannot possibly live in ordinary houses.

Our visit to Nebraska in June 1981 specifically addresses this problem. During our week we are visiting seven people who have either profound or severe mental retardation, and who additionally have severe physical handicaps, severe problems of epilepsy or severely disturbed behavior. We are looking at the day programs, residential and specialty services provided for those seven people by ENCOR, and are interviewing parents, staff and mentally retarded people themselves. We are also photographing extensively - not without some soul-searching, since we find flash photography, particularly in people's houses, to be very intrusive. Slides do, however have a great capacity for focusing people's attention on the "How could we do that?" questions instead of the "surely that's impossible?" ones.

We hope to take back with us then, seven careful accounts, with supportive documents and pictures, to show how in one service - ENCOR, - some severely handicapped people are being served (not always ideally) in the kind of setting we would probably choose for ourselves. The materials we take back will be used as the basis for more workshops and seminars. Of course, demonstrating to people that "it can be done" is only a part of the process. The next thing is to convince them that they should be doing it.

We have gained immensely from our contacts in Nebraska over the past few years. One of the spin-offs has been a steady stream of Nebraskans visiting us by return (whom we welcome!). Hopefully as time goes by, we may be able to take them to see some services from which they too may be able to gain and learn. One of the really interesting things to us, has been that many of the people we meet seem to accept ENCOR's services in a very "matter of fact" way - indeed often asking us for our criticisms. From our point of view, ENCOR offers probably one of the most advanced models anywhere in the world. This does not mean that we are completely uncritical - far from it. But we do think you have something very special indeed here, which must be carefully safeguarded.

Alan Tyne - Organizer, CMH, Education and Research Association

Paul Williams - Tutor Organizer, Castle Priory College, The Spastics Society

June 16, 1981