

# CHURCH- HILL REPORT

by

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Eighteen months of preparatory enquiries and correspondence resulted earlier this year in the writer making a four months tour to four overseas countries and to a number of areas within them. The purpose of the tour was to study the kinds of support services that were being effectively used to help families look after a mentally retarded child at home, or to help the adult who is mentally retarded to live within his local community with only that degree of support that he actually requires. The areas visited and the people responsible for the programme in those areas, are in varying degrees putting into practice the philosophy of the normalization of human services.

What the writer saw in relation to support services for mentally retarded persons and their families is fully applicable, with appropriate adaptations, where services are required for any other types of need — for physically handicapped persons, for old people, for deserted children and so on.

Where the philosophy of normalization is fully appreciated and translated into the details of the service being provided, the focus of attention has completely shifted from a facility to a service, and the focus of interest (of those who will provide the service) centres on the individual and his or her true needs; and by the use of this term 'true' I am referring to the needs as they are exhibited by the person to receive the service and not as they may be perceived by the providers of the service.

This change in attention from providing a facility to devising a service to suit the individual, has revealed a great range of options to meet the great range of individual differences that exist in any population whether people are handicapped or not. In the opinion of the writer, confirmed by persons from various countries, with wide experience of services for mentally retarded people, the system of services available in Eastern Nebraska for persons handicapped by mental retardation is at this time the most comprehensive and effective to be found anywhere. The agency (government) responsible for these services is the Eastern Nebraska Community Office of Retardation, (ENCOR), serving five counties of Nebraska with a population of more than half a million.

Why is ENCOR, this conservative mid-western State in the corn belt, doing something so far ahead of the majority of the rest of the world?

Why does the mention of ENCOR services sometimes bring about the closed lips of resentment in other parts of North America?

My answer to the first question is that in Eastern Nebraska, instead of providing a range of facilities to which application is made for service, the government agency ENCOR goes to a family or an individual with the problem of retardation, and finds out what they see as their needs and then tailor-makes the service to meet that need.

My answer to the second question is that human nature being what it is, there are always people who resent the greater success of others whether they may be individuals or States. And this very resentment is perhaps the greatest tribute that can be paid to what has been demonstrated by ENCOR in Nebraska over a period of six years.

For residential needs ENCOR does not buy or build but rents ordinary houses or flats on a short-lease basis — perhaps a year but often for shorter periods.

# Let's restore the Balance.



Photo by courtesy of Vivian Jenkins and 'Cleo'



## It's not a question of charity. It is a matter of justice.

A handful of rich nations—ours among them—consuming most of the world's resources.

The rest . . . two thirds of the world . . . some three billion human beings . . . living lives plagued by hunger and disease and deprived of basic necessities.

**The have's and the have-not's. On a global scale.**

## You can help restore the balance.

Through Foster Parents Plan you can do something. No, you will not change the world. But you will be assisting a family towards the self sufficiency that is their due as human persons.

We have no political or religious affiliations. Our sole purpose is to help people in the developing nations to help themselves . . . **through the support of those who care.**

### Do you care? Enough to help?

You can sponsor a family in Latin America, Asia or Africa. It will cost you \$14.50 a month. This contribution provides the family with vital counselling, guidance and encouragement from an indigenous social worker. It provides some financial support, medical care, health education and vocational training.

It is small assistance by our standards. Yet it lays a foundation for future progress by the family's own efforts.

**Our objective: not dependency, but initiative and self-reliance.**

### Person to person help.

You will be put in touch with the family and kept informed of its progress. One of the children (the "Foster Child") will

write to you regularly. It need not be just a matter of dollars and cents.

**There can be personal interest and personal involvement.** Perhaps you cannot commit yourself to full sponsorship. Then just send what you can. It will be put to good use in family, community self-help projects and co-operatives.

Foster Parents Plan of Australia is currently at work in Ethiopia, Bolivia, Brazil, Colombia, Ecuador, Haiti, Peru, Indonesia (Bali & Yogyakarta), Republic of Korea and the Philippines.

**Please sign here . . . and help restore the balance.**



**Foster Parents Plan of Australia**

*Established internationally in 1937*

36 Park St., South Melbourne, Vic., 3205. Phone 699 1200 (STD 03)  
N.S.W. Office—P.O. Box 250, Randwick, N.S.W., 2031.

I/We wish to sponsor a child and family for one year or more.

Country preferred (if any) ..... Foster Child should be a boy/girl.

Payment will be made \$14.50    \$43.50    \$87.00    \$174.00  
Monthly                      Quarterly                      Half-yearly                      Yearly

Enclosed \$ .....

I/We would like to know more about sponsorship.

I/We cannot 'sponsor' a foster family but would like to help.

Contribution enclosed for \$ .....

Name (Individual or Group) .....

Address .....

Postcode ..... Phone No. ....

CAM/FPP 4



**Ethel Temby talking with Robert Perske, author of the book "New Directions for parents of persons who are retarded", at the reception for delegates at the Symposium of the International League of Societies for the Mentally Handicapped, Airlie, Virginia, August, 1976.**

Similarly for vocational training ENCOR leases a factory or shop.

Funds are always short anywhere, but ENCOR puts the major part of its resources into the kind of service that can only be provided by people of quality. While the directors of the various divisions of ENCOR — Residential, Vocational, Family Support, Staff Training, etc., — are professionally as well as personally qualified for their positions, the majority of staff persons are selected for their personal qualities regardless of their background education or experience. This also was the case with many staff persons the writer met in Sweden, England and Canada as well as other States of the U.S.A.



Average citizens are recruited by advertisement and if selected for training may have as little as two days of lecture/discussions. However the emphasis on normalization and what this means in the quality of day to day human relationships and the consequent advantages to the person in need of the service, grips the imagination and retains the interest of most recruits.

For residential staff their in-service training is extensive and continuous as the actual delivery of services is localised to within a small geographically defined area, and meetings of staff in that area are held weekly.

For vocational (Industrial Training Centre) staff the training on the job may be under the supervision of a senior staff person, responsible for five or seven clients each with an individual programme plan recorded on paper and reviewed weekly. The combination of these factors enables progress to be seen and gives personal and professional satisfaction to staff members.

The levels of enthusiasm and personal commitment in staff, and the impression that the pioneering spirit of six years ago is still inspiring the system of services of ENCOR, have convinced many enquiring visitors that this a model to reproduce.

It would not do justice to ENCOR to leave out the many aspects of their functioning that develop their separate services into a system of services. 'Setting up a system of

services for mentally retarded people, we found it useful to abandon all of the old shibboleths of times past and establish an individualised flexible system': Ed Skarnulis.\*

This 'individualised flexible system' implies the acceptance that every individual is a developing person and that as they developed their needs for support will vary and probably lessen as their living skills increase. (See figure 1)



The core residence is the hub of the 'cluster system' and for all practical day to day or week to week purposes the cluster is virtually autonomous. Overall responsibility lies with the Director of Residential Services. The diagram indicates the varied nature and the varied staff support of two typical clusters, an adult (Burt Street) cluster and a children's cluster. What is not seen is the variety of family support services that may emanate from the cluster and/or be augmented by services from ENCOR headquarters. In each case a service is devised to meet a particular need for as long as that need exists.

The same kind of support and training for staff of the children's alternative living units (ALUs) is given also to the natural parents, so that the need for residential care outside of the natural home is lessening through the prevention of additional handicaps in either child or family.

\* Ed Skarnulis, Associate Professor, University of Nebraska, Medical Centre, Department of Family Practice, in a paper given in August, 1976 at the Symposium of the International League of Societies for the Mentally Handicapped, entitled, 'Normalization and Integration — Improving the Quality of Life.'

ENCOR engages staff members on an individualised contracting system, so that there may be people engaged to attend a pre-school to help with severely and multiple handicapped children five mornings a week. There may be a number of students at tertiary level engaged to sleep at houses in a cluster simply to ensure that a responsible person is there at night. There may be staff engaged to assist three adults, who are sharing a flat, during their after-work and early evening hours. This assistance will take the form of training in shopping, handling money, preparing an evening meal and perhaps discussing problems related to inter-personal relationships. Whatever the need the flexible creativity of the ENCOR system can devise a way to meet it.



International League of Societies for the Mentally Handicapped — Airlie, Virginia, 1976. Australia was represented by Mrs. Ethel Temby.

Fostering of children is part of the ENCOR care system but this is far more extensively developed in Michigan by the government agency known as the Macomb-Oakland

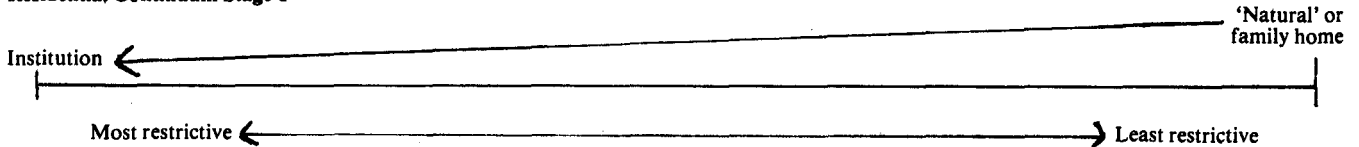
Regional Centre, serving two counties. MORC advertises for fostering families, selects approximately one in twenty-five applicants, gives a short training course (about five lec-

Fig. 1.

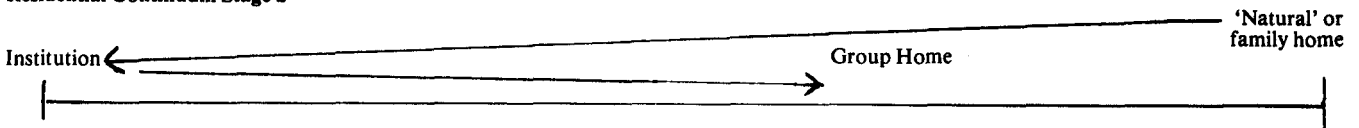
N.B. The range of options shown as Stage 3 were developed in Nebraska in 5 years from Stage 1. 1400 people are (Aug. 1976) now in community living units.

**RESIDENTIAL ALTERNATIVES**

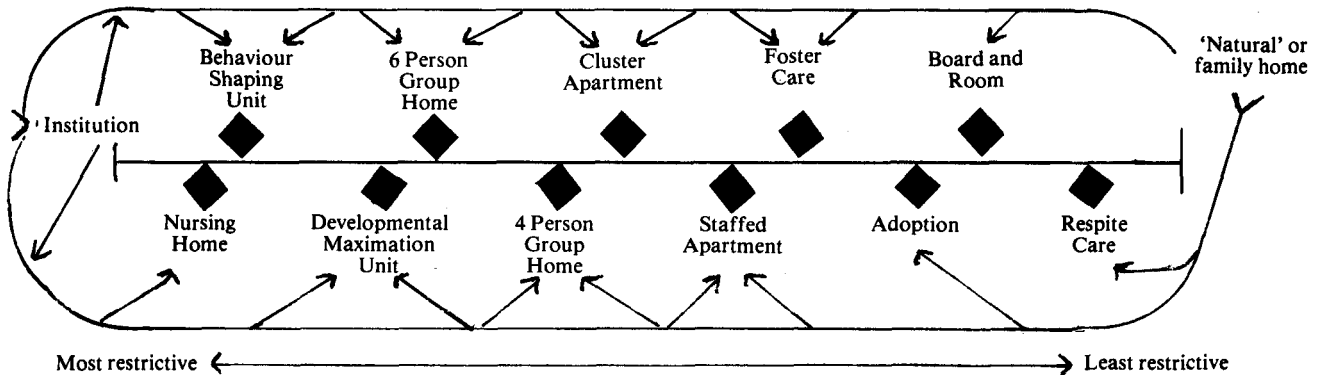
**Residential Continuum Stage 1**



**Residential Continuum Stage 2**



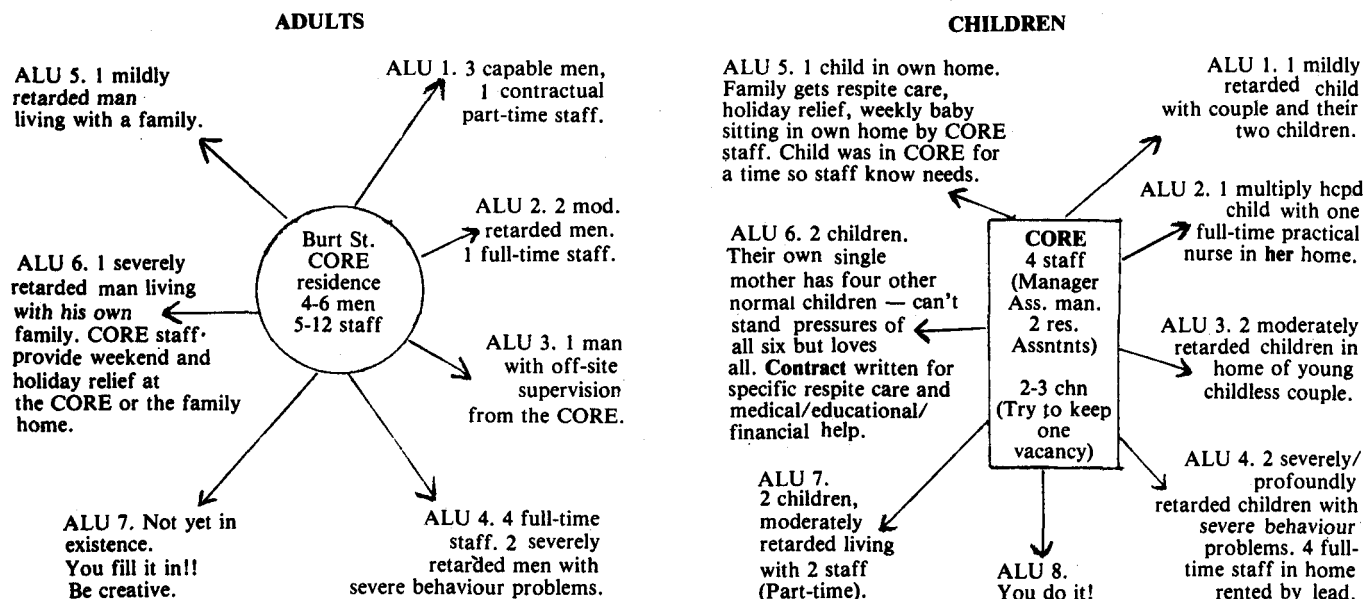
**Residential Continuum Stage 3**



ENCOR, (Eastern Nebraska Office of Retardation) U.S.A., was at Stage 3 in 1975. The Behaviour Shaping Unit has since been deleted as it was found that there was more 'sharing' than 'shaping', but the programme continues one/one).

Fig. 2

EXAMPLES OF CORE & CLUSTER SYSTEM OF ALTERNATIVE LIVING UNITS OF ENCOR (Eastern Nebraska, U.S.A.)



**N.B.** The CLUSTER & CORE FORM A UNIT . . . They MUST NOT be separated. The CORE is vital to the others. They are not just foster homes.

**PRINCIPLES:**

- 1) Start with the person's needs, then look for staff, residence, and other specialised services.
- 2) Don't buy — rent or lease.
- 3) ALU casts will average less than current group home costs if each contract with ALU staff is tailor-made to meet the need of clients.

**N.B.** The CORE is differentiated from the ALUs by its function which is to serve as a receiving residence, holding only as long as necessary to move the person through into a more normal, less restrictive environment. (Comment from Nebraska: "Burt St is too big.")

tures initially) and then places a child with the family. A programmer from the team which has assessed the child, visits the home and works out, with the foster parent, goals to set for the child. These are recorded and weekly comments entered by the foster parent who is supported by twice monthly visits from the social worker and a visit monthly for review of the child's progress by the programmer. The fostering parents are contracted as para-professional staff and are required to attend a later series of lectures and such ad hoc workshops as some of them may request from time to time. These trained foster parents are becoming acceptable to natural parents, as the development of the children in such trained foster care has demonstrated the advantages of this form of alternative care over the congregate life in an

institution.

Also in Michigan through a voluntary agency known as "Spaulding for Children" there has developed a highly successful programme of adoption for 'hard to place children.' Again, as in Nebraska, they see an important factor in their success as being 'discarding all the old shibboleths about matching families and so on! 35% of the children they have placed with adoptive parents have had mental retardation as one of their problems. The Spaulding movement has now developed in four other States, and is bound to spread further.

**Numerous Alternatives**

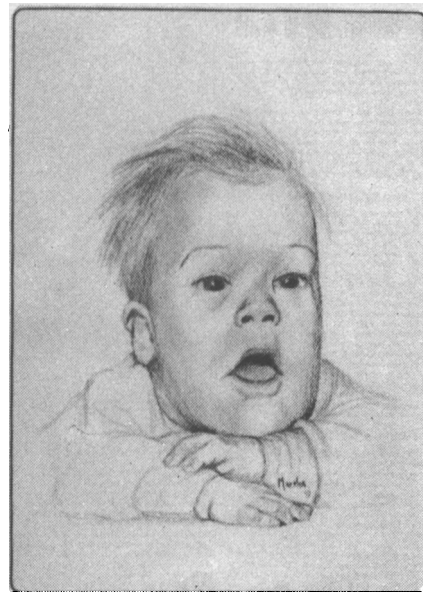
Figure 2. shows the numerous alternatives on the residential continuum of the services in Nebraska in 1975. The Behaviour Shaping

Unit has since been deleted as after two years, it was found that there was more 'sharing' than 'shaping' and that better progress could be made on an individual basis. ALUs 4 in both the Adult and Children's clusters indicate the more effective alternatives.

A few years ago in most western cultures the only alternative to living in the family home was living in an institution. For other children this has changed considerably in Australia but for many retarded children there is still little choice. The development of alternatives between the natural home which is the least restrictive environment and the institution which is the most restrictive, has been slow in this country as in most others. The numbers of retarded children adopted or fostered remain very small compared with those who



A moment of contrast at the League symposium — Mrs. Temby in conversation while the Canadian delegate studies his notes during a break in a session at the Symposium. The Symposium looked at the question "Normalization and Integration — Improving the Quality of Life."



The illustrations on this and the preceding pages are by Martha Perske, and are from the book *New Directions for Parents of Persons who are Retarded*, by her husband Robert Perske. She has given her kind permission for the illustrations to be reproduced.

enter institutions if they cannot live at home. Most of the group home development has been done locally by parent groups concerned with their own children.

Changes are taking place in some parts of Australia. In Nebraska 1,400 people have been placed in community living in six years. Pennsylvania, using the Nebraska model, has settled 2,300 people into community life in only four years. Spaulding had placed over 200 hard to place children in adopting families in the six years to June 1976 when the writer visited that agency. Macomb Oakland reversed a plan to build a 750 bed institution, and, in the time it would have taken to build it, had placed 840 people in various forms of living in the community, with many children in a type of foster care with trained personnel.

The writer has selected these places because of the kinds and quality of support to natural families, to adopting and fostering families and to retarded adults in community setting, that they are providing.

From family home to institution, from institution to nursing home or lonely boarding house has often been in the words of Bengt Nirje,\*\* 'an anguished decision between the horrible and the impossible.'



Nebraska, through ENCOR has demonstrated successfully over six years a far better way. The writer could not hope for a better environment than that provided in the EN-

COR system for her own retarded son. ●

\*\* Bengt Nirje, Co-ordinator of Training, Ministry of Health, Ontario, Canada. Formerly while Executive Director of the Swedish Association for the Mentally Retarded one of the originators of the principal of normalization.