

NATIONAL ASSOCIATION FOR
RETARDED CITIZENS
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DATE 11-6-74

TO: Peter Polloni
FROM: Eleanor Elkin

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Eleanor

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FOR RETARDED CITIZENS

Elaine - type
Bee. also to:
Polloni
Brown
Schmidt
Burda
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Charles
D.

Alternatives to Institutions

RECEI

Presented by Sean S. Eskin

Chairman, NARC Residential Services
and Facilities Committee

at The 3rd Congress of The

Caribbean Association on Mental Retardation

October 19-23, 1974, Bridgetown, Barbados

PENNSYLVANIA
FOR RETARDED

The preparation of this paper was a challenge which was approached with a sense of humility. Our goals — to help people who are mentally retarded, to grow, to develop, and to live a good life, — are the same, but our problems are different.

You do not need to initiate programs to change institutions and to overcome the dehumanization of residents which has been the result of years of living in a large institution. Too often the inappropriate structure, the overcrowding, the understaffing and meager programs of our residential facilities has caused many staff members and even some parents to become institutionalized in their attitudes and really believe nothing can be done. Of course, This becomes a self-fulfilling prophecy and nothing

progressive is done.

You do not need to plan extensive and expensive deinstitutionalization programs.

You do not need to fight the self-perpetuating interests of administration, labor, civil service, and commerce surrounding an institution. A big institution is big business for a small town.

We hope you have learned from us what not to do. We hope you will not copy our mistakes. We hope you will learn with us what can be done. There is so much we, at this Congress, can share to help each other. The National Association for Retarded Citizens, in the U.S.A., has published "The Right To Choose" which you may find helpful. Much of what I say you will find in this book.

The International League of Societies for the Mentally Handicapped and the United Nations' Declaration of the Rights of the Mentally Retarded Person states "Wherever possible the mentally retarded person should ~~not~~ live with his own family or with a foster family. The family with which he lives should receive assistance ----." Before moving a child from the family every effort should be made to maintain the home.

~~Ed~~ Ed Skarnulis, who is responsible for establishing residential facilities in the ~~area~~ community in Nebraska, has had several years experience establishing group homes, hostels, apartments and foster homes. He believes these residences are good, but he keeps telling us that it is better to support people in their homes than build, buy or rent places for them.

So the first thing we must do, when considering placement away from home, is ask "what is needed to keep this child or adult at home?" "What is it that is making it so difficult for the rest of the family?" Perhaps a daily visit by the Public Health nurse to give a bath will relieve the mother of ~~a back breaking chore and make the difference between despair~~ the chore that was breaking her back and spirit. Maybe provision of laundry or diaper service will make the difference.

~~Between~~ A positioning chair, wheel chair or lifting device may be necessary to ~~other~~ help the handicapped person and his family. Of course they are expensive but not as costly as care away from home. Perhaps all that is needed ~~is~~ is for the handicapped person and his family to have a separate vacation. Short term homes can also provide intensive behavior ~~or~~ changing or other program help. Supplemental income ~~to all~~ for the family so that the mother does not have to work & can care for her handicapped child should be available.

If needs can not be met at home, then a residential service must be found which will promote the

individuals growth and dignity. It should provide a home environment with supervision as needed.

It should afford living experiences appropriate to the functioning level and learning needs of the individual.

This residence should be located in the mainstream of community life and provide access to program services to meet the individual's developmental needs.

~~Residential services, therefore, must be developed using certain basic principles.~~

The basic principles which underly a nation's cultural value system and legal guarantees should apply equally to its mentally retarded citizens. Residential services, therefore, must be developed using these principles.

- 1- Retarded children and adults have the same rights as other children and adults.
- 2- Retarded children and adults are capable of learning and development. Each individual has potential for progress, no matter how severely handicapped.
- 3- Retarded individuals should be helped to live as normal a life as possible. Daily routines, life style and physical environment should be as near to the normal cultural pattern as possible.
- 4- Retarded individuals should be treated so as to promote emotional development. They must not be treated as children all their lives because they ~~do~~ do not have the opportunity to learn adult

behaviors.

5. all programs for mentally retarded persons must contribute to increasing the complexity of the individual's behavior, the ability of the individual to control his environment and the self control of the individual.

Programs must maximize those qualities which have been culturally designated as normal and which enhance a person's human qualities.

6. Program objectives should be designed to meet the needs of each individual and will vary for different degrees of impairment. The goal is to significantly heighten ^{his} personal social and vocational development.

7. The individual's personal goals should be given consideration ^{when} designing programs. Contrary to some opinions, most retarded persons are capable of communicating their desires and aspirations ~~and~~ for their future. Of course, the individual, as well as the family, should participate in planning a change of residence.

8. The community is the focal point for delivering service to citizens. Therefore, community ^{services} education, recreation, ~~health~~ rehabilitation, health and mental health should be used to the fullest extent. The aim must be ~~the~~ integration. Segregating services must not be set up when generic services are available.

In Omaha, Nebraska, there is a program called Children Helping Children. It is for ~~the~~ children of pre-school age and is for handicapped and non-handicapped children. ENCOR, the ~~Omaha~~ agency ~~is~~ responsible for service to mentally retarded people, has contracted with several private nursery schools for admission of 4 or 5 handicapped children. As part of the contract ENCOR supplies the nursery school with a "resource teacher" skilled in working with the retarded child. This resource teacher, like the other teacher works with all the children in the nursery ~~as~~ school but is available to assist ~~the~~ them with them ~~as~~ with any problems with the handicapped children. The non-handicapped children have accepted their handicapped peers with very little fuss, and are also very good models ~~for this~~ ~~and~~ and provide the handicapped children with the ~~tensions, and joy of growing up~~ every day experiences necessary for growth and development.

9. Living arrangements should be separate from program services. A person should not sleep, work, play, study and receive all services in the same place. Movement is important in ~~acquiring~~ ~~in developing skills according to~~ developing the social awareness and the skills necessary to deal with a more complex environment.
10. No program should be considered terminal. There must always be a developmental goal.

Residential service placement must be viewed as a part of an individual's Total program and not a place to put somebody.

~~living arrangements~~ There can be as many different kinds of ~~arrangements~~ as there are needs for ~~help in their~~ ~~best~~

There can be as many different kinds of residences as there are needs for living arrangements away from the natural home. Foster homes for 1 or 2 children is perhaps the most desirable and "normal" arrangement. (It is important for foster parents to have good consultation available to strengthen their home.) Temporary homes for emergency, respite or vacation were discussed briefly. Homes that provide learning experiences and support to enable a ~~person~~ person to move to independence; apartments ~~that~~ ^{that} can allow semi-independent ~~functioning~~. (That is just a minimum of supervision) or independent living group homes for children who need developmental help ~~but~~ ~~is~~ so they can ~~not~~ live ^{with} some success in their natural or foster home; 5-day homes for children who live far from the school they must attend; residences for the elderly are examples of homes that some communities have established with success.

People often ask about the design of a

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residential facility for retarded persons. We agree with ~~Arnold~~ ~~Gagnes~~, The rule-of-thumb put forward by Arnold Gagnes, Chairman of the Architecture Committee of The International League. It should be a home like the other homes in the neighborhood? Would you ~~live there~~ want to live there?

It is important to have the support of the community. Therefore, government, business, ~~citizens~~, parents, ~~other~~ citizens, including centers of influence, parents should be involved from the early planning included in the planning group. They should also be included in the advisory committee as the facility develops.

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It has been said that small residential facilities can be just as dehumanizing as a large institution. This is true but it is much easier to see abuses in the house down the street — especially if we look. ~~Community homes must be monitored + evaluated regularly.~~

Build Provision for regular monitoring and evaluation should be included in the plan for operating of operation. Programs and environments can be evaluated according to the degree to which they ~~fulfill the goal~~ meet the needs of each individual they serve. You should ask "What is happening to Mary? Has she moved forward because of this

program?

Many communities are setting up advocacy services. Usually the advocates are volunteers. They are people who care about people. They interact on a one-to-one basis with handicapped persons offering support in social and emotional areas. Advocates help their protégés obtain their rights and when necessary, protect them from abuse and exploitation.

Yes, we are our brothers' keeper, — ~~not~~ not keeper in the sense of custodian, keeper in the sense of advocate ~~and~~ friend. Wise + kind people have put a sign on a door of a facility for multihandicapped children. It reads — "Caution - Human beings inside".

(over)

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*we would add "a
responsible"*

To: Handle with care! / As They
accomplish their goals the
sign should be changed
to read "Caution - Human
beings inside - coming out!"