

COMMUNITY-BASED RESIDENTIAL SERVICES

A RESOLUTION OF THE NATIONAL ASSOCIATION FOR RETARDED CHILDREN IN ANNUAL DELEGATE CONVENTION ASSEMBLED, URGING THE GOVERNMENTS OF THE STATES TO ESTABLISH SMALL, COMMUNITY-BASED, HOME-LIKE RESIDENTIAL FACILITIES FOR THE MENTALLY RETARDED.

WHEREAS, the subject of optimum residential services for the mentally retarded is currently receiving high-priority national attention, and

WHEREAS, it is now recognized as the normal and desirable right of handicapped persons, including the mentally retarded, to live their lives as normally as possible, surrounded by the everyday community and integrated with that community life, and

WHEREAS, recently established accreditation standards, the expert opinions of leading professionals in the field of mental retardation and the President's Committee on Mental Retardation, and a landmark decision of the United States District Court, Middle District of Alabama, reflect that existing residential facilities are frequently inadequate, inhumane, isolated, sub-standard and misdirected, and

WHEREAS, it will be a function of the government of each state to reach decisions about replacement residential facilities, and to implement these decisions within their state, and

WHEREAS, no such state government should undertake decision-making affecting the mentally retarded without giving full consideration to the recommendations of those persons who can best speak for the mentally retarded.

NOW, THEREFORE BE IT RESOLVED BY THE NATIONAL ASSOCIATION FOR RETARDED CHILDREN:

That the National Association for Retarded Children recognizes that the public interest requires that additional residential facilities for the mentally retarded must be constructed, purchased or leased.

BE IT FURTHER RESOLVED, that the National Association for Retarded Children recommends that such residential facilities be community-based and be integrated into the main-stream of community life.

BE IT FURTHER RESOLVED, that the National Association for Retarded Children recommends that such residential facilities consist of small living units, each replicating a normal home environment to the closest extent possible.

BE IT FURTHER RESOLVED, that the National Association for Retarded Children recommends that such residential facilities take absolute precedence over further capital investments in existing or new large scale "institutions."

BE IT FURTHER RESOLVED, that the President of the National Association for Retarded Children be requested and instructed to send a copy of this resolution to the governor of each of the 50 states, a copy to the president of each state and local unit member of the National Association for Retarded Children, and copies to such other persons as he may deem advisable.

October 1972

FIRST ACCREDITATION

The Accreditation Council for Facilities for the Mentally Retarded began conducting surveys in April 1972 in specially selected facilities on a field test basis. As a result of the review of the first surveys conducted, the Arizona Training Program at Tucson, Arizona became the first residential facility for the mentally retarded to be accredited under the new program.

The Accreditation Survey focuses on assessing compliance with the Standards for Facilities for the Mentally Retarded as evidenced in the daily activities of a stratified sample of facility residents. The surveyors select a representative sample of residents, examine their records, observe their activities, and talk with the direct care staff personnel who are responsible for each resident's daily activity. Ten to twenty such in-depth reviews ("Program Audits") are carried out in each facility that is surveyed by the program.

Each facility for the mentally retarded seeking accreditation is required to complete a self-survey using the Survey Questionnaire. The Questionnaire is reviewed by the Council's surveyors prior to the onsite visit, and it provides the information base for the survey.

A grant awarded by the Division of Developmental Disabilities, Social and Rehabilitation Service, U.S. Department of Health, Education and Welfare, will support the continued development and improvement of the Council's standards and survey procedures.

Implications of Accreditation Standards

Following the pattern set in Alabama — where a federal court has ordered the state institutions for the retarded to meet standards drawn from the **Standards for Residential Facilities for the Mentally Retarded** (ACFMR) — suits have now been filed in several other states alleging that inadequate treatment in state institutions for the retarded violates the constitutional rights of the residents.

ACCREDITATION COUNCIL PROGRESS REPORT

Since July, applications for accreditation survey have been sent to 73 facilities. Completed applications have been returned by 32 facilities. On-site surveys will be conducted after the facilities complete the self-study phase of the accreditation process. It is felt that facilities are being slow in filing their applications, and in subsequently completing their Survey Questionnaire, so as to have more time to bring themselves into compliance with standards before the survey occurs. While this situation delays the start of the Council's survey program, it is, of course, consistent with the goals of motivating facilities to improve their services.

Among other evidences of the Council's impact on the field are the facts that committees have been established in each New York State institution for the retarded to evaluate present compliance and to plan to bring the institution into compliance. The Pennsyl-

vania Office of Mental Retardation plans to require private residential facilities that it licenses to be accredited, with provision for funding the cost of the survey by the state. The Illinois Department of Public Instruction is exploring the possibility of requiring that all special facilities from which it purchases services be accredited by the Council. The Massachusetts Association for Retarded Citizens is sponsoring the introduction of legislation requiring all state-operated residential facilities for the retarded to apply for accreditation and to be surveyed annually. A publication of the Arizona Department of Mental Retardation reports that plans have been made to bring the existing facility at Coolidge into compliance with the Council's Standards within five years, and that the new facility to be built in Phoenix will conform to the Standards. The Florida Department of Health and Rehabilitative Services has requested applications for all its mental retardation facilities.

INSERVICE PROGRAM DESIGNED TO CHANGE ATTITUDES

Cottage parents at the Ellisville State School in Mississippi are participating in a new approach to inservice education. The Institute for Epistemic Studies has developed an extension study program which provides regular seminars and work-related activities designed to focus upon the individual value systems which support constructive attitudes toward retarded persons.

Through individual and group confrontation with underlying values and attitudes, the participants are forced to examine the consequences of their own behaviors upon the lives of the mentally retarded residents. Participants in the new program submit regular diary entries to the Institute, which makes individual comments and suggestions before returning the material to the participants.

A spokesman for the Institute noted that one of the greatest barriers to improving programs and achieving accreditation is the low expectations held by staff members for the resident's development and potential return to the community. The spokesman said, "Institutional personnel are actually quite capable of helping the retarded person make enormous strides toward greater independence, but staff members have, in the past, been taught to hold very infirming attitudes toward retarded individuals, considering them to be hopelessly handicapped. When these underlying attitudes change, the institution's efforts at individualized programming can go forward."

For more information contact: The Institute for Epistemic Studies
2719 Cockrell Avenue Fort Worth,
Texas 76109

INSPECTION AND CERTIFICATION OF NURSING HOMES: A NEW MILESTONE

A massive federal effort to upgrade longterm care facilities reached a milestone on July 1, 1972, the announced deadline for cutoff of federal support to substandard nursing homes. As of that date each state

must have completed certification of all skilled nursing homes providing care to Medicaid patients.

Under the regulations states determined by HEW to have failed to complete the inspection and certification of all skilled nursing homes face formal compliance hearings. All states stand to lose federal financial participation for the homes they have not yet certified. If valid certification of these homes is achieved at a later date, financial aid will resume on the first day of the month in which certification occurs.

As a result of implementation of the above program — reports *American Medical News*, July 31, 1972 — federal funds were withheld from 579 nursing homes for failure to meet minimum standards of health and safety.

The Undersecretary of the U.S. Department of Health, Education and Welfare, reported that 327 nursing homes — 222 of them in New York State — lost their certification. Another 252 homes withdrew from the program because they were unable or unwilling to meet the standards.

Of the approximately 7,000 homes receiving federal nursing home aid, 1,469 received full certification and 4,766 were certified for six months to give them time to correct deficiencies not affecting health and safety, and an additional 244 were still in the certification process.

The report covered only nursing homes receiving federal aid under the Medicaid program, leaving out the approximately 16,000 for the elderly not receiving such assistance.

From *Action on Community
Problem Solving, The United Way
of America*, October 1972

ALTERNATIVES FOR THE 1970'S

(Excerpts from a paper given by Kenneth Bayes, of England, at the First Regional Conference of the United Kingdom Committee of the World Federation of Mental Health.)

It is obvious that we cannot suggest what kind of buildings will be needed until we have decided what kind of life the retarded should live.

What one finds among all progressive thinking is an emphasis on the well-being of the individual mentally retarded person . . . the personal principle . . . to regard retarded people as human beings of body, soul and spirit, each a unique personality like you and me, with a like need to find personal identity and fulfillment.

It is interesting to realize that looking outside the field of retardation we also see the struggle for the expression of the individual, under the threat of bureaucracy and mechanization, as the dominant factor in world unrest. It is worth noting that the impulse which inspires our present efforts in mental retardation — the principle of normalization for the individual — is the same impulse that underlies the apocalyp-

tic age in which we live, the struggle for the freedom of individual conscience, for the triumph of the personal principle.

Much building today is sadly within the category of "thing architecture," concerned with site values, property development, pompous monuments to the owner (or the building benefactor or the architect). The nearest it gets to considering people is in terms of areas in square feet, optimum temperatures and air changes.

But people architecture — giving first importance to the complete needs of the wide diversity of the individual human beings who use the building — is gaining ground. It has given birth to the hybrid discipline of architectural psychology. It leads to an architecture which allows for human failings and inconsistencies, weaknesses as well as strengths.

What is the first environmental right of the individual adult human being? The right to be alone, for privacy, territory to call his own, the right to enter and leave it as he likes, to invite others into it, to exclude others from it, to decorate and furnish it. What next? To live with a small group within which some degree of intimacy, understanding, mutual trust can develop; within which each individual can cooperate in daily tasks, conflicting personalities and differing attitudes can be experienced, endured or enjoyed.

What else? To be able to enjoy a social life among a large and more varied group, to contribute to the community as far as ability allows, to be able to form friendships outside the home and to entertain friends, to be free to socialize or not according to mood.

If we take this seriously, accepting these individual needs as the main criteria for future planning, what does it mean in terms of architectural design and building cost? Let us look first at the implications for existing institutions. Upgrading schemes have been carried out in many countries motivated by this very concern for the welfare of the individual resident. Large wards have been subdivided by screens, by room dividers to provide the privacy of an individual bed-space. Day rooms have been broken up by fitments, by planting, to form activity areas — for games, for quiet pastimes, for TV, etc. This has resulted in enormously improved conditions and a far more tolerable life for the residents and for the staff. But I sadly believe it to be an impulse which is attempting the impossible. At the end of 10 years or so we shall have an improved but a very inadequate environment.

The age, size and type of building which generally constitute the old institutions make it impossible to produce by alterations, additions, or modernization the conditions demanded by our new attitude about the retarded. These buildings can never, even with the greatest ingenuity or imagination, be turned into units which are domestic in both size and atmosphere. The old institutional building is insatiable in its capacity for swallowing resources, but we must deny its appetite. We must stop pouring money into these buildings and stop using them as soon as possible. But in the mean-

time we must not neglect either the resident or staff who occupy them. Limited resources will have to be spent, not on alterations to structure — but on small things of domestic life — furnishings, china, household things that are now sadly lacking but which can make a big difference to the pleasure of daily living.

It is obvious that new houses can be designed to provide for privacy and for small group relationships and that if there are enough of them together, a social life can develop. In other words, even if these requirements cannot be met by alterations to existing buildings, it might be argued that they could be satisfied by new building on the institution sites.

This is not a valid argument, in my opinion. First, because of the right of the handicapped person to grow up and live among us in society. Secondly, because of the right of the average person to have mentally handicapped people around. Put in another way, the handicapped have a right to give to us and not only to take from us.

The new housing, therefore, should be in the community. The essence of its design must be that it is as normal as possible, where the occupant will live a life of maximum independence. The size of the group must always be small. There is no magic number. Even a small group will need a somewhat larger house than average, but it can and should be thoroughly domestic in appearance and in scale. A severely handicapped resident will need a ground floor bedroom and a carefully laid out bathroom. But these are variations on the general theme of family living. Designing for community care must be looked at with a fresh eye.

It is sometimes said that the advocates of community care are too impatient, are not willing to change slowly.

My answer is twofold. First, if changing slowly means upgrading existing institutions we shall be spending too much on comparatively little to be able to afford any real change at all. Secondly, the nature of change is that it takes place not in an orderly sequence of even steps, but in rhythms. It seems that now after long years of quiescence the wheel has turned to a time for radical change.

There is a danger of "community care" becoming a soporific term of good intentions. When the time comes we may find that Hell is largely paved by pages from draft White Papers for the mentally handicapped. Individuals, societies and governments are all too liable to express pious hopes, adopt the new gospel, invite Scandinavians to lecture — and leave it at that. When it comes to facing up to the practical implications of phasing out the Subnormality hospitals, of training the right staff, of really evaluating the true cost, enthusiasm tends to wane. But this is not necessary; community care is a practicable proposition.

To sum up: What do I see as the task of the 70s?

1. The first and overriding task, because it determines all others, is a devotion to the personal principle

in relation to the retarded, to the rights and freedom of the individual handicapped person.

2. Applied to a building program this means that only minimum resources must be spent on upgrading. The Subnormality hospitals cannot provide the answer for the future and must be phased out.

3. There must be no more new building on Subnormality hospital sites, even temporary structures, because overcrowding must be solved by decanting into the community.

4. Major resources must be concentrated on the provision of community care — the only care which will really give the physical environment to meet the rights of each mentally handicapped person.

If we have the will and the determination, this program can be achieved during this decade.

GROUP HOMES — STATE OF WASHINGTON

Since 1966 more than 1000 residents of Washington's institutions have been returned to their families or other community living situations. This return of institutional residents marks a complete turnabout in programs for the mentally retarded, both in direction and in philosophy.

For almost a century, state government had assumed responsibility . . . from one modest facility serving seven people in 1890, to seven institutions serving 46,000 residents in 1967. All were overcrowded and waiting lists were long.

The answer lay not in more institutions. Given adequate and varied community support, many could leave the institutions, and others need never come.

The State of Washington became the first state to adopt as a mandate the POLICY STATEMENTS ON RESIDENTIAL CARE adopted by NARC in 1968. To aid residents toward habilitation, a vigorous educational and training program was begun; selected placements were increased, while admissions criteria were redefined. The goal was to provide a better life for the more capable in the community, (who would still be under institutional jurisdiction) and in turn, to be better able to serve the more severely and multiply-handicapped in the institutions.

Community based programs grew.

With these resources at hand community residential placements increased in accordance with the philosophy that all must be in the best interests of the individual and with family compliance. Institutional doors are never closed against returns. Some individuals have successfully become independent, others have returned to home and family, gone to nursing homes, boarding homes, other sheltered living and/or working situations — and most recently — group homes.

In 1969, the Group Home Bill authorized the Director of institutions to place residents of institutions into group homes and pay for their continued support.

It defined a group home as "A residential facility capable of serving a small number of mentally and/or physically handicapped individuals — up to a maximum of 20— who are able to participate in a variety of jobs, sheltered workshops, day care centers, activity centers, educational facilities, and/or other community based programs that are meaningful for their training, rehabilitation and/or general well-being."

Dr. Samuel Ornstein, Chief, Office of Developmental Disabilities, wrote, "Group homes provide an individual with the opportunity to progress at his own rate, unhampered by the artificial confines of an institutional ward."

As the number of group homes increases, their distinct personality and ability to serve individuals becomes more and more evident because Washington's group homes are not of stereotyped design — they are almost as varied as their numbers.

Eight mildly retarded young ladies live — like sisters— in a white house nestled in a fruit orchard. All attend school in the community. By contrast, architecturally, at least, a complex of three homes, once a fabulous show place, boast a Grecian-styled swimming pool, and extensive landscaping. The houses have been remodeled and refurnished for 35 young adults, both men and women. Each weekday they go to Yakima where each is assigned to a training center geared to his needs and capabilities.

The University of Puget Sound sponsors two group homes for 17 young retarded children who are also emotionally disturbed and/or autistic.

This program may be the first of its kind in the nation to enlist private, state and federal funds to aid children thus handicapped. Each home is fully staffed, has a full-time teacher, part-time psychologist, and many volunteers. Recreational facilities, including a swimming pool, are also available.

Twenty elderly, mildly retarded ladies who had lived together most of their lives at Lakeland Village, now enjoy their home in Spokane. This older home has several fireplaces, overlooks a park, and has a delightful gazebo in the yard. The ladies, who are quite self-sufficient take pride in keeping the house spotlessly clean.

Several of the original residents of group homes have moved into apartment complexes, but are still receiving some supervision from the management of their former group home.

As against the mass regimentation of institutions, group homes more nearly approach family living. There must be rules and regulations to assure safety, orderly living, and respect for the rights of others, but regimentation is kept to a minimum. Residents are encouraged to develop as individuals, to assume responsibilities, to make decisions, and are challenged to participate in community activities. Equally important, the residents of the community are urged to welcome them into their churches, businesses, schools, restaurants, parks and recreational centers—not as a novelty or an act of kindness — but because they are

learning that the handicapped can adapt, and that they belong!

The self-developing, self-directing programs of these group homes are expanding as much as their administrators' imaginations and finances allow. New resources are opening wherever there are group homes.

For more information or a copy of the *Group Homes Standards & Guidelines* manual, contact the Office of Developmental Disabilities, P.O. Box 1788, Olympia, Washington 98504.

PRIVATE FACILITIES REVIEWED

The Pennsylvania Department of Public Welfare has trained review teams in each of its four regions. On-site visits to 58 facilities, with 1900 residents, began Monday, October 2 and was completed by Wednesday, October 25.

The goal of the Inspection Teams was to guarantee the delivery of high quality residential services to the mentally retarded in accordance with their needs, by setting new state standards for service, determining the present compliance with these standards in helping existing facilities to meet the standards that were feasible. Each on-site Inspection Team included a mental retardation specialist from the county MH/MR program, and a representative from a consumer or parent group.

The review of the facilities was accomplished in two phases. First, the On-site Observation Team made inspections of physical conditions and observed program activities, and held personal interviews with staff members and residents. It documented its findings for assessment by an Independent Review Team.

In Phase II, each Regional Review Team assessed the data collected by the On-Site Teams, evaluated the status of each facility on the basis of its functional capacity to provide safe, healthful and socially desirable services; its capability to program effectively in keeping with the individual needs of residents, and its potential for continued use by county MH/MR program facility for the retarded.

(From—PENNSYLVANIA MESSAGE, Nov. 1972, PARC, Harrisburg, Pa.)

INTERNATIONAL LEAGUE PUBLICATIONS OF INTEREST

Architectural Principles and Mental Retardation, 1972, International League of Societies for the Mentally Handicapped, Bruxelles, Belgium.

Report on International Symposium on Cooperation Between Parents, Clients and Staff, Copenhagen, November 1971, International League of Societies for the Mentally Handicapped, Bruxelles, Belgium.

Report on International Symposium on Volunteers, October 1971, Philadelphia. Co-sponsored by The President's Committee on Mental Retardation, and the National Association for Retarded Children; International League of Societies for the Mentally Handicapped, Bruxelles, Belgium.

ROLE OF ATTENDANTS EMPHASIZED

A series of significant changes has begun at Lapeer State Home and Training School, Michigan's largest institution for the mentally retarded. Albert L. Meuli, the superintendent, said "Our goal now is to develop the retarded to the maximum of their potential and return them to the community. This requires that institutions provide rapid, effective, individualized training programs."

"The question is: how can we best reorganize our resources to get the job done? I'm starting on the premise that if anything is going to get done it is primarily the attendants who are going to do it."

In order to pinpoint the needs of the resident the Lapeer staff has developed the Lapeer Adaptive Behavior Profile (LABP) based on a similar but much longer rating scale compiled by the American Association on Mental Deficiency.

The LABP is a two page evaluation covering the wide range of basic human behavior. Major categories include independent functioning, physical development, language development, community functioning, social skills, and personality development.

Every resident at the institution was evaluated in virtually every area of human adjustment from putting on shoes to social interaction to speech patterns and eccentric personal habits. The goal is to pinpoint in specific written terms the problems of residents as well as the responsibilities of individual staff in resolving those problems.

There are only three choices in evaluating a resident in a specific area: Yes — the resident can consistently perform as indicated; no — the resident does not demonstrate mastery in the area; maybe — the resident can perform this behavior but needs additional training and/or assistance.

As an example, one of the areas listed under independent functioning is cleanliness. Ward staff makes a determination about five specific behaviors in this area.

1. Can wash face and hands
2. Can take a bath unaided
3. Keeps self clean
4. Can brush on teeth/denture care
5. (Females) Cares for self during menstruation

In total, 112 different behaviors are rated. This information provides the tool to design the rest of the programming.

The Lapeer staff expects to update the LABP every six months so that determinations can be made of approximately how much progress has been made and what further training must be completed. Several computer programs are being refined so that results of the LABP evaluations will be rapidly available in the appropriate form to both ward staff and administration.

Because the evaluations concentrate as much on assets of residents as they do liabilities, it is believed that judgments about suitability for community placement can be made more quickly and accurately.

For more information, contact:

Mr. Dennis Heifer, Lapeer State Home and Training School, Lapeer, Michigan 48446
(From—THE LINK, Michigan Department of Mental Health, Lansing, Michigan, 1972)

VACATION — WITH PAY

All Selinsgrove students on community work placement earn at least one week paid vacation after one year of employment. Many of the students have no families to visit and could not vacation away from their residences. This year nine students spent a week at Hershey.

They stayed at a motel, toured the chocolate factory, went to drive-in movies, and church, and took their first airplane rides.

The students learned about traveling in practical repeated experiences — how to purchase a variety of meals, lodging costs and the tipping procedures.

At the end of a week no one wanted to return to work ... a sure indication of success.

(From CHATTERBOX, Selinsgrove State School and Hospital, Selinsgrove, Pa.)

PLANNING PRESENTS ALTERNATIVES

Institutional life is not the only solution to the problem of the mentally retarded. Finding the alternatives and presenting them to the parents of a mentally retarded child will be the job of the new Alternate Planning Unit of the Austin State School.

The Alternate Planning Unit was begun as part of a growing belief that most mentally retarded persons function more effectively when they remain in a home and community living situation. The new unit is funded under a grant from the Department of Public Welfare as a purchase of social services from the Austin State School professional staff.

The unit staff is composed of a director, two caseworkers, two caseworker aides and two secretaries. Several staff members are bi-lingual, and have personal knowledge of Mexican-American cultural patterns. The unit will work in the communities to develop alternative placements among hometown resources. They will be talking with both residents and parents about their lives and problems as they help them to understand and select an alternative to institutional living.

Residents will also receive help in developing communication skills.

(From CAMPUS CHATTER, Austin State School, Sept. 1972)

THE RIGHT TO LIVE

By Eleanor Elkin

The tragic story of the infant with Down's Syndrome, sentenced to death from starvation by parental command, opened the Joseph P. Kennedy, Jr. Foundation's International Symposium on Human Rights, Retardation, and Research in October 1971. This film, "Who Shall Survive" is now famous and has been the subject of many articles, letters and discussions. It is important that we continue to examine the issues it raised because it is not an isolated incident.

In April 1968, THE ATLANTIC MONTHLY carried an article titled, "The Right to Die", by Bernard Bard, a writer for the New York POST, and Joseph Fletcher, a professor of theology and Christian ethics at the Episcopal Theological School in Cambridge. Mr. Bard described the agony of being told his new-born son suffered from mongolism, an incurable condition, and was destined to be grossly retarded. The Bards placed their infant son in a private sanitarium and the doctor was told that nothing was to be done to extend the baby's hold on life artificially. Mr. Bard was assured that while medicine could not take the child's life, nothing would be done to prolong it. No operations would be performed, no miracle drugs would be administered. Medical emergencies, such as sudden bleeding or choking would be met and the child would be kept warm, fed, and sheltered. Nothing more. The sanitarium contained no oxygen. The children were given no inoculations against childhood diseases. "There are churches on all sides of me," the doctor said. "Every one of these ministers agrees with me that it would not be moral, or serving God's will, to prolong these lives."

This tormented father wrote, "On the trip home, I prayed for my child's death, cursing and damning myself as I did." The prayer was answered. Philip died within a few hours of heart failure and jaundice. Mr. Bard concluded his part of the article, "I did not know my son. I do not know his thousands of brothers and sisters . . . I do not know the parents of these children. I do not speak for them, just for myself, and perhaps for Philip. I believe that it is time for a sane and civilized and humane approach to euthanasia." ". . . there are thousands of children on this earth who should never have been born. Their lives are blank. They do not live or love. Their life is without meaning to themselves, and an agony to their families." "WHY?"

It took great courage for Bernard Bard to write those desperate words. He had made his decisions based on what he had been told. It is too bad that nobody told him that his child was so weak that death was imminent. It is too bad that nobody told him that retarded children need not have blank lives, that even the most limited can be helped, that they respond to loving and mothering. He could have been spared some of the anguish and had a more loving memory of his son's few days of life.

Joseph Fletcher, the professor-theologian, describes Bernard Bard as a loving man who "cares" too much for human happiness and peace and kindness and loving concern to subordinate every other consid-

eration to merely keeping breathing a sadly non- or un- or sub-human creature." He says, "In dealing with Down's cases, it is obvious that the end everybody wants is death." And further, "People in the Bards' situation have no reason to feel guilty about putting a Down's syndrome baby away, whether it's 'put away' in the sense of hidden in a sanitarium or in a more responsible lethal sense . . . True guilt arises only from an offense against a person and a Down's is not a person."

Mr. Fletcher is obviously ignorant about Down's syndrome. The "person" of the child with Down's syndrome can not be questioned. Ask any parent or teacher of a retarded child and they will describe a child capable of expressing both joy and frustration, a child who can be fun-loving, naughty, and responsive, a child who returns love and affection and joy in abundance.

Louis Novak, a 15 year old boy with Down's syndrome, died by forced drowning at a private residential facility in Pennsylvania. My purpose in speaking about his tragic death is not to make accusations, but to point out some of the attitudes and behaviors exposed at the hearings and in interviews. His mother said that she had been advised by community social workers and mental retardation specialists to send her son away from the pressures of home and community for his own good. The place selected was described as a wonderful school where her son would be with his own kind and receive training that neither she nor the community could provide. (She was not told that the school had only been able to obtain a provisional license because of past and present violations of standards.) The "clincher" was the judgment that if she did not do this for her son she would be a very selfish woman. How cruel to use a mother's concern and love to send a retarded member of the community 200 miles away. After Louis' death television interviews with residents and tradesmen of the town in which the special school was located indicated that the community felt no guilt or responsibility for what happened "up there on the hill." One man, who sold the young men candy, magazines and other small items when they came into town, indicated that he wasn't disturbed by rumors of mistreatment of these young men. He said, "After all they're retarded . . . retarded urinate on the floor and do other things all over. They're retarded — what do you expect?" All of these attitudes, decisions and behaviors had their origin in the fact that Louis was retarded, not that Louis was a boy (a person) in need of help.

Peter A. Kiefer, Executive Director, Green Bay Center, responded to the film "Who Shall Survive" in an article in THE CENTER POST: "In the entire life of the retarded individual he is singled out as being somehow different in the most basic ways . . . What we have done it seems to me, is to deny that a retarded individual is just that — an individual — but is a member of a homogeneous group, all possessing the same characteristics. This can only lead to the very situation which we now have. If the retarded (persons) are different, (they) must be treated not as members of the community, but separate from the community . . . unless all of us — parents, professionals and the gen-

eral public accept the fact that the retarded (individual) is an individual person and make our decisions with the realization that he is a person, we cannot expect to break down attitudes which tend to lump (retarded people) in a group which is outside the mainstream of society. The decision to choose not to perform an operation on a baby should be made based on the fact that he is a person, not that he is retarded."

The staff of the Boulder River School and Hospital, Boulder, Montana, has proposed the following LIFE PROLONGING POLICY: "In the event that a patient has deteriorated or is deteriorating to a level that is dehumanizing as a result of either uncontrollable environment or genetic insult, and it is apparent that there is no possibility of a return to a meaningful level of human experience, it is the policy of the Boulder River School and Hospital that its medical staff shall not necessarily provide such a patient with life prolonging procedures."

"In such an event the medical staff and the individual physician shall be governed by the policies and ethics of the American Medical Association.

"In the event of admittance to hospital for, or a change, while in hospital, to such a condition, and the initiation of such a program takes place, the parents and/or legal guardian(s) of such patient shall be informed or promptly notified of the program and a properly executed confirmation of their awareness of such program shall be entered into the patient's medical record."

Gene Patterson, NARC Program Consultant, wrote in response, "As a philosophical statement, its destructiveness is possibly even more significant in that it is an insidious type of dehumanization rather than the more easily recognized overt variety. It would seem infinitely more dehumanizing to *avoid* prolonging life since it would imply a lack of concern with human life. When a policy says basically that some individuals are less valued than others and that their lives are of no importance to the society, then we are returning to the socially destructive philosophy of an aristocracy — for us that question was settled at Gettysburg."

In Pennsylvania the U.S. District Court ruled that all mentally retarded children have a right to a free public school education.

In Alabama the U.S. Justice Department set forth the right of retarded persons to treatment.

We are gaining recognition — slowly — of the retarded person's right to live in the community. Per-

haps the reason progress is slow is that there are those who would deny him not only his right to live in the community, but even his right to *Live*.

The United Nations General Assembly in its Declaration on the Rights of Mentally Retarded Persons states, "The mentally retarded person has, to the maximum degree of possibility, the same rights as other human beings." That means he has the same rights you and I claim to LIFE, liberty and the pursuit of happiness.

Yet it is still necessary to discuss whether or not a retarded person should be allowed to survive.

There is a large task before us ... to change the attitudes and behavior of people toward their brothers who are mentally retarded. First, we must state clearly that the person who is mentally retarded is first of all a person — more like than different from other people; that like all people, he is a unique individual¹ and as such has his own contribution to make to society; that all retarded people can be helped — including the most profoundly handicapped. Next we must proclaim retarded person's rights as set forth by the Constitution of the United States of America and the Declaration of the United Nations. Then we must aggressively resume the struggle to restore to them their right to live among us in the community because they are our brothers, our children, and our friends.

SIOUX FALLS APARTMENTS

Funded by both HEW and HUD, the Housing and Redevelopment Commission in Sioux Falls, South Dakota has developed an apartment program to provide non-institutional housing for adult physically disabled and mentally handicapped families and individuals who are capable of independent or semi-independent living. The goal of the program is the construction of 35 apartments in several locations throughout the city with minimal supervision.

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The *Record* is published three times a year by the Residential Services Committee of the National Association for Retarded Children, 2709 Avenue "E" East, Arlington, Texas 76011. Editor, Mrs. Eleanor Elkin.

IF YOU WISH TO RECEIVE THE RECORD ...

The mailing list for THE RECORD is being updated. If you wish to continue receiving your copy, or if you wish to have your name added to the mailing list it is necessary that you send your name and address to **Gene Patterson, Department of Program Services, National Association for Retarded Children.**

The new mailing list will be used for the Spring, 1973 issue.