

a national symposium

NURSING HOMES

in the system of
residential services



NURSING HOMES
in the System of
Residential Services

Proceedings
of a National Symposium
May, 1975

NATIONAL ASSOCIATION FOR RETARDED CITIZENS

Arlington, Texas 76011

Contents

	Page
FOREWORD	i
SYMPOSIUM AGENDA	iii
LIST OF SPEAKERS	v
WELCOME Eleanor Elkin	1
STANDARDS AND REGULATIONS Susan Weiss	3
THE NURSING HOME SETTING Henry Lynch	19
APPROPRIATENESS OF NURSING HOME SETTING James Clements	29
HUMAN AND CIVIL RIGHTS J. Stanley Pottinger	47
INDIVIDUAL ASSESSMENT Marie Moore	61
THE INDIVIDUAL PROGRAM PLAN Patricia McNelly	73
ENVIRONMENTAL ISSUES George Gray	85
FAMILY INVOLVEMENT Kathryn Gorham	95
COMMUNITY INTERACTION Allan Bergman	105
ADMINISTRATIVE ISSUES David Rosen	119
REACTOR PANEL Rita Charron Henry Lynch Dolores Norley	129

	Page
COMMENT Philip Vaughn	135
PROGRAM EXAMPLE - ENCOR UNIT Karen Green	137
SUMMARY Philip Roos	147
WORKSHOP: THE INDIVIDUAL PROGRAM PLAN Gene Patterson	157
NARC POSITION STATEMENT: Nursing Homes in the System of Residential Services	171

Foreword

During the last decade there has been an ever increasing national effort towards seeking new residential alternatives so as to reduce the size of large public institutions for retarded citizens. Deinstitutionalization has become a major focus of the Federal Government and is having direct repercussions on state and local government postures towards seeking improved models of care. Nursing homes and intermediate care facilities have come directly to our attention as representative of smaller residential alternatives. Yet these alternatives have posed unique problems of their own, such as the overall appropriateness of these settings for retarded citizens. Questions have been raised in regard to definitions of nursing care, which special program features must be included, environmental issues, standards and regulations, accountability, financial dimensions, etc. These problem areas were viewed as a challenge by the NARC Board of Directors who, seeking to further explore these issues, elected to hold a national symposium on Nursing Homes in the System of Residential Services. We initiated and funded this symposium with the intent of bringing together interested leaders in this area of endeavor from both our nation's professional community and our own Association.

The purpose of the symposium was to enunciate basic guiding principles which can be utilized by parents and professionals to assess (and enhance) the appropriateness of nursing home settings for mentally retarded persons. The proceedings reported herein represent a serious and concerted effort to attain this purpose. They constitute an extended presentation of the issues involved in serving retarded persons in nursing home settings. Beyond the issues surrounding the appropriateness of nursing homes, one notes herein an abiding concern for attempting to enhance the lives of retarded citizens wherever they reside. I was pleased to note this focus on individual needs as a recurrent trend throughout the proceedings.

The speakers at this symposium addressed themselves to the general and specific dimensions of the current and future roles of the nursing home in serving retarded citizens. We are indebted to the participants for their mutual sharing of ideas and recommendations.

Frank J. Menolascino, M.D.
President, NARC
1976

NURSING HOMES in the system of residential services

National Symposium: May 8-9, 1975

Chairman & Moderator

Eleanor Elkin

Thursday, May 8:

8:00 a. m.	Registration	
9:00 a. m.	Welcome and Overview of the Symposium	
9:15 a. m.	Standards and Regulations	Susan Weiss
9:45 a. m.	The Nursing Home Setting	Henry Lynch
10:30 a. m.	COFFEE BREAK	
11:00 a. m.	Appropriateness of Nursing Home Settings	James Clements
12:00 Noon	Discussion	
12:30 p. m.	LUNCH	
2:00 p. m.	Human & Civil Rights	J. Stanley Pottinger
2:30 p. m.	Discussion	
2:45 p. m.	Individual Assessment	Marie Moore
3:30 p. m.	Discussion	
3:45 p. m.	COFFEE BREAK	
4:15 p. m.	The Individual Program Plan	Patricia McNelly
4:45 p. m.	Discussion	
5:15 p. m.	Orientation to Evening Workshop	Gene Patterson
5:30 p. m.	ADJOURN FOR DINNER	
7:30 p. m.	Workshop on Individual Program Plan	Gene Patterson Patricia McNelly
9:00 p. m.	ADJOURN FOR THE DAY	Marie Moore

Friday, May 9:

9:00 a.m.	Feedback from I. P. P. Workshop	Gene Patterson
9:30 a.m.	Issues Influencing Programs Environmental Issues Family Involvement	George Gray Kathryn Gorham
10:15 a.m.	COFFEE BREAK	
10:45 a.m.	Issues Influencing Programs Community Interaction Administrative Issues	Allan Bergman David Rosen
11:40 a.m.	Reactor Panel	Rita Charron Henry Lynch Dolores Norley Joe Winters
12:15 p.m.	LUNCH	
2:00 p.m.	Program Examples ICF/MR Unit (Central Wisconsin Colony) ENCOR Unit Macomb-Oakland Unit	Patricia McNelly Karen Green David Rosen
3:00 p.m.	Summary and Wrap-Up	Philip Roos
4:00 p.m.	ADJOURN SYMPOSIUM	

NURSING HOMES

in the system of residential services

FACULTY

Allan I. Bergman
Executive Director
San Francisco Aid Retarded
Children, Inc.
1362 Ninth Avenue
San Francisco, California 94122

Rita Charron
Director, Programs for the
Mentally Retarded
606 West Shiawassee Street
Lansing, Michigan

James D. Clements, M.D., F.A.A.M.D.
Director, Georgia Retardation Center
4770 North Peachtree Road
Atlanta, Georgia 30341

Eleanor S. Elkin
Chairman, NARC Residential Services
and Facilities Subcommittee
5555 Wissahickon Avenue
Stafford House - Apt. #915
Philadelphia, Pennsylvania 19144

Kathryn Gorham, M.A.
c/o Montgomery County ARC
11212 Norris Drive
Silver Springs, Maryland 20902

George V. Gray, F.A.I.A.
Director, Mental Hygiene Planning
Facilities
State of New York
44 Holland Avenue
Albany, New York 12208

Karen Green, R.N.
Developmental Maximization Unit
4102 Woolworth
Omaha, Nebraska 68105

Henry H. Lynch
Administrator, The Lynch Home
205 Krewson Terrace
Willow Grove, Pennsylvania 19090

Patricia C. McNelly, R.N.
Director of Nursing
Central Wisconsin Colony &
Training School
317 Knutson Drive
Madison, Wisconsin 53704

Marie Moore, O.T., M.S.
National Advocacy Coordinator
Professional Services
Program Department
United Cerebral Palsy Associ-
ations, Inc.
66 East 34th Street
New York, New York 10016

Dolores Norley, F.A.A.M.D.
211 - 30th Street
West Palm Beach, Florida 33407

Gene Patterson, M.S.N.
Consultant, Program Services
National Association for Retarded
Citizens
2709 Avenue E East
P.O. Box 6109
Arlington, Texas 76011

J. Stanley Pottinger, Esq.
Assistant Attorney General
Civil Rights Division
Department of Justice
Room 1232, Todd Building
550 - 11th Street, N.W.
Washington, D. C. 20530

Philip Roos, Ph.D.
Executive Director
National Association for Retarded
Citizens
2709 Avenue E East
P.O. Box 6109
Arlington, Texas 76011

David Rosen, F.A.A.M.D.
Director, Macomb-Oakland
Regional Center
36358 Garfield Road
Fraser, Michigan 48026

Susan Weiss
Assistant Director
NARC Governmental Affairs Office
The Federal Building
1522 K Street, N.W.
Suite 516
Washington, D.C. 20005

Joe Winters
19 N.W. 41st Terrace
Kansas City, Missouri 64116

Overview

Eleanor Elkin

It is a great pleasure to welcome you to A National Symposium - Nursing Homes in the System of Residential Services. We are delighted that you are here, and we are impressed with the wide areas of interest and occupations from which you come, such as parenting, government, nursing, management, social work, child development, advocacy, etc. If we had handpicked you, which we didn't quite do, we couldn't have assembled a more diverse and broad interest group. We are going to run a tight schedule, but there will be discussion periods. We hope that every one of you will be asking the questions that are on your mind and telling us what you think. We urge your participation. Remember that there is a session tonight. Tonight you will working on actual problems about real life people.

Since its founding in 1950, NARC has stated that its principal objective and purpose is to promote the general welfare of mentally retarded persons of all ages wherever they may reside. A current goal of our Association is to "achieve an array of developmental institutional and community-based residential services for all mentally retarded persons, ensuring the possibility of choice among a series of alternatives."

goals

Within the last few years there has been increasing use of nursing homes and intermediate care facilities for mentally retarded and other developmentally disabled individuals. The demand for deinstitutionalization, coupled with the availability of Medicaid money, has caused many state governments

and providers of services to consider skilled nursing and intermediate care facilities as a solution to placement problems. They are being used to reduce the number of people in institutions, to allow delicate, developmentally disabled children to be served near their home. They are also being used for the aging retarded person, and sometimes, I am afraid, as just a place to "put" people. Unfortunately, not all have provided quality services. Recent hearings in Washington have revealed many instances of misuse and abuse. There is a growing debate over the appropriateness of the nursing home setting for the retarded and developmentally disabled person.

Recognizing the potential value, as well as the dangers, of nursing home and intermediate care facility placements, NARC's subcommittee on residential services decided to take a positive step to finding solutions to these problems. A number of letters were sent to other organizations and agencies asking if they thought a symposium on the appropriateness of the nursing home setting was feasible. With one exception, which came from one of our own local units, everyone who responded felt it would be valuable and gave us information about problems and issues they would like discussed.

We planned a program around these responses so that our symposium was designed to examine some of the critical issues that you and your colleagues see. It was designed to focus on the individual developmentally disabled person and his program needs while exploring the limits, the capabilities and the appropriateness of the nursing home setting in the evolving service delivery system.

the individual
and his program
needs

Standards and Regulations

Susan Weiss

The Federal Government invests a great deal of money in nursing home care. In 1974, more than 2.5 billion dollars in federal funds flowed to the states to pay for the care of persons living in nursing homes. Of that 2.5 billion dollars, more than 400 million dollars were earmarked to support mentally retarded persons living in state institutions and in other, smaller residential facilities.

The federal nursing home program covers two different types, or "levels," of care: "Skilled nursing care" and "intermediate care." Both Medicare, which is the federal health insurance program for elderly and disabled persons, and Medicaid, which is a federal/state program to pay for the cost of medical care provided to low-income persons, cover skilled nursing care, but only Medicaid will pay for intermediate care.

types of
care

From the national perspective, the number of mentally retarded residents receiving skilled nursing care is extremely limited. It is so small, in fact, that the Federal Government doesn't even bother to identify the mentally retarded patient in a skilled nursing facility as a separate category in their statistics. The skilled nursing facility is one which is designed to care for persons with acute medical problems - the mentally retarded individual, for example, with serious multiple handicaps who requires round-the-clock professional nursing care. The skilled nursing program was conceived as a medical program and the Federal regulations

the skilled
nursing facility

which govern skilled nursing facilities strongly reflect that orientation. The regulations deal with nursing coverage, the administration of medication, and other aspects of caring for the acutely ill or critically fragile patient.

the
intermediate
care facility

For our purposes, the major federal nursing home program which impacts on mentally retarded persons is the intermediate care facility program - the ICF program.

Although ICF's are often referred to as nursing homes, the term is a misleading one because the federal definition of an ICF embraces a broad variety of residential care settings - the state schools for retarded persons, some halfway houses for alcoholics, the nursing home for the elderly, some group homes for retarded people. All of these diverse facilities can be embraced under the ICF umbrella.

Public Law
92-223

It was not until 1972 that the Congress passed Public Law 92-223 which authorized, for the first time, federal support under Medicaid to pay for the care of persons in intermediate care facilities. Prior to 1972, only skilled nursing home care could be paid for through Medicaid.

Under Public Law 92-223, the ICF program is an optional one. That means that the states are not required to cover intermediate care in their state Medicaid plan. If they choose to do so, however, the Federal Government will reimburse the states for a portion of the cost of providing intermediate care to eligible persons. The percentage of the federal share varies from state to state, depending upon the state's average per capita income; but as a national average, it runs in the neighborhood of 50 per cent. If the state decides to include intermediate care in its state plans, it must then decide whether or not it wishes to cover intermediate care in specialized facilities and institutions for retarded persons. This is a second option and to date, 37 states have opted to include ICF services for retarded persons in specialized facilities.

ICF definition

According to the federal law, an ICF is defined as an institution which provides "health related or rehabilitative care and services to individuals who do not require the degree of care and treatment which a hospital or skilled nursing home is designed to provide, but who, because of their physical or mental condition, require care and services above the level of room and board. . ."

As you can see, a very broad spectrum of residential settings meets the rule of "more than room and board, but less than skilled nursing" care.

When the Congress passed Public Law 92-223, they wrote into the law an extremely important provision, setting the stage for implementing the ICF regulations which were later issued by HEW. The Congress stipulated that no Medicaid funds could be used to pay for the care of any retarded person living in an intermediate care facility unless that person was receiving what the Congress called "active treatment."

What does active treatment mean? According to HEW, "Active treatment means an aggressive and organized effort to fulfill each resident's fullest functional capacities. It requires an integrated, individually tailored program of services directed to achieving measurable behavioral objectives. It requires an environment approximating, as closely as possible, the patterns and conditions of life in mainstream society. It has as its goal the development of those skills, habits and attitudes essential to adapting in contemporary society. It means equipping each resident who is able to return to community life"

active
treatment

Thus, the Congress and HEW have designed a program which is not custodial in nature. Rather, they envision an ICF for the retarded as a place where things happen, a place where people learn and grow, an environment where growth is assumed and where the concept of a retarded person as a static, rigidly limited being is explicitly rejected. By requiring active treatment as a condition of Medicaid support, the Congress served notice that it expected the intermediate care facility program to provide a high level of quality programming and that it expected the intermediate care program to expect a considerable reform of current institutional conditions.

a place where
people learn
and grow

On January 17, 1974, HEW published final regulations to interpret this congressional mandate and to establish minimum requirements which every ICF must meet if it is to receive Medicaid support.

ICF regulations

Generally speaking, the regulations are compatible with the developmental approach to programming. They are not based on the so-called medical model, although some states have chosen to interpret them in that light. But the regulations themselves are reasonably consonant with developmental concepts.

The core requirement in the ICF regulations is the requirement that each resident must have an individually tailored program plan which must

establish specific behaviorally-stated objectives for the resident and must prescribe an integrated program of services, therapies and experiences which are designed to achieve those objectives.

interdisciplinary
evaluation

The program plan must be based on an interdisciplinary evaluation of each resident, covering, as a minimum, physical, psychological and social status and conducted by an interdisciplinary team. The initial evaluation must, in addition, consider whether or not the individual truly requires institutional placement as opposed to other less restrictive care settings.

This evaluation must be conducted periodically, but in no case less often than annually. At the time of the annual review, the progress of each resident must be assessed and the continuing appropriateness of his program must be reviewed and revised accordingly. Each annual review must consider again the possibility of alternative placement in a less restrictive environment.

The regulations have as their ultimate goal the deinstitutionalization of every ICF resident for whom this is possible. For this reason, the regulations require that a post-institutionalization program plan must be developed for each and every resident at the time of his or her admission.

qualified
personnel

The regulations also require that at least one "qualified mental retardation professional" be assigned overall program responsibility for each resident and his plan of care and services. The concept of the "qualified mental retardation professional" first gained federal attention when it was incorporated in the court order in the Wyatt v. Stickney case in Alabama, the first right to treatment case. Under the ICF regulations, it is the role of the qualified mental retardation professional to supervise the implementation of the resident's program plan, to coordinate the provision of services called for in that program plan and to initiate periodic reviews of the plan, as necessary, but not less often than annually. The qualified mental retardation professional may be drawn from any of a number of professional backgrounds. He or she may be a psychologist, an educator, a social worker, a physician or a nurse - so long as he or she has the requisite specialized training or experience in mental retardation.

Regulations require that each resident must participate in a daily living training program designed to assist the resident in acquiring or improving self-help and social skills. In addition to his training program, each resident must receive a full spectrum of specialized and professional

services as those services are called for in the individual's program plan. These services include physical and occupational therapy, audiology and speech services, psychological services, social services, recreational programming, health services (including an annual physical examination) and emergency and routine dental care.

In the area of the physical environment, the regulations require that every facility must meet the Life Safety Code. Where a facility accepts physically handicapped residents, it must additionally comply with the ANSI standards. The ANSI standards, of course, are designed to make facilities accessible to, and functional for, physically disabled persons by eliminating architectural barriers. Finally, in the area of physical environment, the regulations require that no more than 12 persons may share a bedroom. By 1977, the maximum number of residents permitted in a sleeping room will be limited to four.

physical
environment

In the area of staffing, the regulations provide that the facility must be administered either by a licensed nursing home administrator or by a qualified mental retardation professional. The regulations require sufficient direct-care staff to conduct the daily living training program and a direct-care supervisor who is accountable for that program. By 1977, explicit staffing ratios must be met. Professional staff are also required or, in their absence, contractual arrangements with community resources to provide professional and other specialized services which are required by the residents. Finally, the ICF must employ, or have contractual arrangements with, enough qualified mental retardation professionals so that each resident's program plan is the responsibility of one such individual. The qualified mental retardation professional, of course, can supervise simultaneously the programs of a number of different residents.

staff
requirements

The regulations I have just briefly outlined for you are in effect today. By March of 1977, every ICF which is a specialized facility for retarded persons or other developmentally disabled persons must meet an additional, more stringent, set of requirements which are based on the standards developed by the Accreditation Council for Facilities for the Mentally Retarded (AC/FMR). I believe most of you are familiar with those standards. The AC/FMR standards, of course, were developed with active NARC participation. I don't have sufficient time to review those standards, so I will simply note they call for a level of programming which is considerably more stringent than that called for in the current ICF regulations.

1977
regulations

On May 4, HEW published an additional set of regulations enumerating the rights of residents in intermediate care facilities. These

regulations are not yet final. They are proposed regulations. NARC has submitted extensive comments to HEW on those regulations for their consideration in preparing final requirements. We think that those regulations constitute an important recognition on HEW's part that the residents of ICF's don't leave their rights on the doorsteps upon admission. Nevertheless, we feel that the regulations, in general, need to be tightened and strengthened. They are couched in very general terms and their enforcement, for that reason, will be difficult.

rights of
residents

At the present time, the proposed regulations governing the rights of residents in intermediate care facilities provide for the following:

1. Confidentiality of records;
2. Freedom from physical abuse;
3. Safeguards governing the use of physical and chemical restraints;
4. The right to privacy in treatment and in caring for personal needs;
5. The right to associate and communicate freely and in privacy;
6. The right to counsel and representation;
7. The right to retain personal clothing and possessions;
8. Safeguards on the transfer and discharge of residents;
9. Safeguards on the financial management of residents' funds and the rights of residents to manage their own resources;
10. The right of the resident not to perform services for the facility unless those services are therapeutic in nature and are included in the individual's program plan;
11. The right of married persons to privacy and to shared living quarters;
12. The right of the resident to participate in the planning of his or her own program.

Where a resident is adjudicated incompetent under state law, however, or where a physician certifies that a resident is incapable of exercising or understanding these rights, HEW's regulations provide that these rights devolve on the resident's guardian, next of kin or sponsoring agency.

This, in brief, is an outline of HEW's current regulations affecting intermediate care facilities for mentally retarded and other developmentally disabled persons. Rather than go into them in any greater detail, I would like to raise some of the issues which I think these regulations present.

ISSUE #1: GROUP HOMES AND ICF'S

Perhaps the major controversy surrounding the ICF regulations at the present time is their application to the small group home. It is extremely important to understand that the ICF program, in the mind of both the Congress and HEW, is one designed for the individual with continuing "health-related or rehabilitative" needs. The individual needing ICF care is one who requires an intensive level of programming; one who requires a comprehensive spectrum of habilitative services. Certainly, many persons living in state institutions and in other large centralized facilities will fall into that category. But this is much less consistently the case for the residents of group homes.

health related
or rehabilitative
needs

Some group homes should be ICF's - those which provide an intensive level of programming and those which take direct responsibility for the provision of services, either by providing those services directly by their own staff or through contractual arrangements with community resources to provide required professional services. Where such a group home contracts with community resources, the facility itself must retain overall program responsibility, coordination and accountability if it is to be considered an ICF by HEW. Where this is not the case, the group home cannot properly be considered an ICF facility. Community-based facilities which provide a modicum of social supervision, where responsibility for daytime programming is not vested in the facility or paid for by the facility or supervised by the facility - such a group home is not an ICF in HEW's mind.

For this reason, the regulations are designed with the larger, more centralized facility in mind. However, some provisions have been incorporated (although not enough) to accommodate the different service style of the smaller, community-based ICF. The regulations also stipulate that in the case of facilities with 15 or fewer residents, compliance with the institutional occupancy provisions of the Life Safety Code is not required. Rather, the facility must meet the residential sections of the Code, which are much less restrictive.

Secondly, such facilities are not required to have any nursing personnel, if a physician certifies that none of the residents, in fact, need professional nursing services and if the group home contracts with a public health service nurse or other visiting nurse to visit the facility as needed to deal with minor medical emergencies and like situations. Finally, as I noted before, professional services required by residents may be provided through contracts rather than directly by facility's staff.

The point which I want to emphasize to you is that the ICF program must be used judiciously, to support the development and the operation of facilities which provide the kind of programming envisioned in the ICF regulations. The ICF funding stream should emphatically not be viewed as a panacea for all of our financial difficulties in providing a continuum of residential services - if we do this, we will find ourselves con-torting programs to obtain federal dollars. I don't believe that this justified.

ISSUE #2: IMPACT OF THE ICF REGULATIONS ON INSTITUTIONAL REFORM

The ICF regulations - and particularly the regulations which must be met by 1977 - call for a level of programming which very few of our institutions will be able to meet without major expenditures. The institutions will have to hire substantial numbers of staff, both direct-care and professional staff. They will have to renovate those large dormitory sleeping rooms so that 40 persons no longer sleep in a room.

You won't be surprised to hear that many of the states have protested vociferously the reforms which are mandated in the ICF regulations on the grounds that the available funds are simply not sufficient to bring these institutions into compliance by 1977. Thus far, HEW has held firm in not diluting the standards, but as the deadline of 1977 approaches, we may expect that the pressure from the states will mount.

From the point of view of the consumer, the institutional reforms required by the ICF regulations raise a different issue. Is it worth it to spend thousands and thousands of dollars to renovate and upgrade our institutions, or would we be better off channeling our limited resources into developing community programs? Will the impact of the ICF regulations ultimately be to divert previous funds from the community into the institutions?

I understand and respect the concern behind such questioning. But I feel very strongly that the need to develop community programs must not become an excuse for ignoring our institutions. The people who live in these institutions deserve better. They must be afforded an opportunity to acquire those skills which will enable them to live in the community. Where that is not a possibility at the present time, the residents of our institutions must be afforded the possibility of a lifestyle which is interesting, which has room for growth, which has room for personal fulfillment.

At the same time that I believe this is true, I think that the ICF regulations impel the states to take a more careful, soul-searching look at their long-range plans for residential services than has been the case in the past. Some hard decisions need to be made. A state would be reckless, in my opinion, if it opted to bring every institution up to the part of the ICF standards simply to get Medicaid funding, without considering whether it was worth it in terms of the ultimate service product which could be obtained from that particular institution. Some of our institutions, no matter how much money is put into them, will have a very hard time ever providing the kind of environment we seek for retarded citizens. The decision of whether or not to upgrade to the level of ICF regulations needs to be made by the states on an institution-by-institution basis.

Here again, if the ICF program is used judiciously, it can be an important force in upgrading the conditions in our institutions and in forcing the states to engage in the kind of planning which will provide for a full spectrum of residential services in the near future.

ISSUE #3: THE GENERAL ICF AND THE MENTALLY RETARDED RESIDENT

The third issue I want to discuss with you is the mentally retarded resident who finds himself in a general ICF. You will recall that I said earlier that the ICF definition embraces a broad variety of different kinds of facilities. Facilities designed specifically for mentally retarded and other developmentally disabled persons are referred to by HEW as ICF/MR's, and must meet the special ICF/MR standards which I have just outlined for you. Other kinds of ICF's, however, the so-called "general" ICF's, are required to meet the general ICF standards which call for a much less stringent and intensive level of programming than one finds in the ICF/MR regulations.

Thus an incentive is created for the state to place mentally retarded residents in institutions which are not required to meet the ICF/MR regulations; for example, the general ICF which is a nursing home for aged persons. For this reason, some states have begun to transfer mentally retarded residents from state institutions which were unable to comply with the ICF/MR regulations and to place those residents in general ICF's. By doing this, the state can continue to claim Medicaid support for that resident without having to invest the thousands of dollars which are necessary to meet the ICF/MR standards.

When NARC became aware of this practice, we wrote to HEW, requesting that HEW issue a policy to the states requiring every ICF, including general ICF's, to meet the full ICF/MR standards if even one of their residents was retarded. HEW did not accept NARC's recommendations in toto, but it took a major step in that direction. It issued a policy to the states stating that general ICF's with mentally retarded residents had to demonstrate that each mentally retarded resident's special needs were being met or lose their certification, their license, to receive Medicaid funding.

Although this policy is a step in the right direction, it is also a policy which has certain problems. The major difficulty, from my point of view, is that the determination that an individual's needs are being met is left to the nursing home inspector or surveyor and to the independent professional review team, which is a group of professionals who may not have any particular expertise in mental retardation.

There has been some talk in HEW, at very high levels of HEW, of revising this policy on the grounds that it is simply too costly to require geriatric nursing homes to provide specialized services to their retarded residents even where the resident requires such services. But, as of today, that policy has not been officially changed, and I can assure you that NARC will do everything it can to see that the needs of retarded residents in general ICF's are met.

ISSUE #4: THE MEDICAL ENVIRONMENT OF THE ICF PROGRAM

One of the most critical issues in the ICF program is raised by the bureaucratic environment, the administrative structure, in which the ICF program must operate. Although the ICF regulations themselves are reasonably consonant with developmental concepts, the overall atmosphere and context in which the ICF program operates is not. The

Medicaid program, after all, is a program designed to pay for health care provided to low income persons. The people who administer the Medicaid program, at all levels of federal and state governments, often are people who come from a medical background. They are nurses, physicians, hospital administrators, people with degrees in public health. They are not people who necessarily have any special understanding of mental retardation. This can create serious problems, even where the administrators are people of abundant goodwill.

For example, the surveyors of nursing homes, the people who are charged with inspecting ICF's to see that they meet federal standards, are very often nurses or generalists. They know little about mental retardation. When such a surveyor enters an ICF for the retarded, be it a small group facility in the community or a large state institution, he or she is very likely to be more concerned with the administration of medications than he is with cooking classes for the adolescents who are likely to move shortly into a less restrictive setting in the community.

This is entirely natural, but it has two very unfortunate consequences. First, the surveyor may certify a facility which provides very poor programming, from our point of view, but which is sparkling clean and has an abundance of white uniforms in evidence. Secondly, a facility with no white uniforms but an abundance of normalized programming may find itself cited by the surveyor because of the lack of a medical environment.

In an effort to remedy this problem, HEW last Fall conducted five training courses for surveyors of ICF's with mentally retarded or other developmentally disabled residents. These courses were an excellent start; however, only five courses were held. Each course lasted five days and only a very limited number of the total surveyors in this country were able to attend. NARC has continually pressed the Office of Nursing Home Affairs in HEW to conduct more such training programs. They are urgently needed, but thus far HEW has neither conducted any such courses nor even scheduled them.

But the problem extends further than just the surveyor - the official who makes decisions may also have a medical orientation and his interpretations and policy decisions on the regulations will reflect that orientation. So, although the regulations themselves may permit developmental programming, the administration of the program itself is medically-oriented.

This medical perspective on ICF's is not limited to HEW and the various state agencies administering the Medicaid program. The U. S. Congress also, quite naturally, views the Medicaid program as a health program. As a result, we find that the ICF for retarded persons is increasingly asked to relate to an administrative structure created by the Congress which is medical in nature.

utilization
control

For example, the Congress has recently passed a series of laws which are designed to put into effect a utilization control system over Medicaid expenditures. The term "utilization control" refers to a series of review mechanisms designed to look at the appropriateness of care paid for by Medicaid and to hold down unnecessary expenditures. The utilization control system has three different aspects. Each ICF must have a utilization control committee, an internal review mechanism which is charged with reviewing such matters as average resident length of stay and other indicators of utilization of services. Utilization control also involves independent professional review teams, interdisciplinary teams of professionals, independent of the ICF administration, who are required to review each resident's program for its appropriateness; the independent professional review team must also consider whether or not institutional placement is required for ICF residents. Finally, there are so-called Professional Standards Review Organizations (PSRO's) which are not yet fully operational in all of the states. These PSRO's, when they are operational, will replace the utilization review committees and the independent professional review teams, and will assume their functions. The PSRO's, you will be interested to know, are staffed and run by physicians, according to federal statute. It is clear that these various review teams, staffed and run by and large by physicians and other health care professionals, are not the best equipped persons in the world to review services and placements of mentally retarded ICF residents. But that is mandated by the law.

surveyor
orientation

I am not raising these issues to discourage you from becoming involved in the intermediate care facility program - that's the last thing I want to see happen. Instead I am raising them because I believe they form an important backdrop in understanding the ICF program and in recommending changes. To a certain extent, you and I are able to influence the medically-oriented perceptions which are held by HEW officials, state agency officials and the surveyors. We need to take the time to clearly explain to them what we mean by developmental programming. We need, wherever possible, to invite these officials to see programs in operation, to satisfy any unease they may have with the efficacy of a non-medical setting for retarded persons. I suggest that we hold training courses for

surveyors at the state level. To arrange for this, all one needs to do is contact the state licensing department and ask to speak to the supervisor of the ICF surveyor program. These are classic instances where a little prevention can go a long way in preventing a medical interpretation of the ICF regulations.

The enforcement of these regulations is a part of all of our jobs. If these regulations are to be correctly applied in a manner consistent with developmental concepts, we must be prepared to teach, to train and to assist officials who are charged with administering, applying and enforcing these regulations. If these regulations are to be strictly enforced in state institutions, we must be prepared to challenge the findings of surveyors, when institutions which you and I know are wanting, are nevertheless found to be in compliance with federal regulations.

enforcement
of regulations

You can, and you should, request a copy of the surveyor's report when you believe a facility has been improperly certified. These findings must be made public on request, according to federal statute. Where the surveyor's findings are not in accordance with your own experience in a particular facility, where the findings are not consistent with your understanding of the regulations, go back and look at the regulations again and be sure that you have properly understood them. If you then feel that you are on firm ground, bring the matter to the attention of the HEW Regional Office of Long-Term Care. Ask them to perform what is called a "validation survey," where federal officials go into an ICF, or other facility, and review and validate the findings of the state surveyor.

surveyor's
report

I hope this discussion will help you to identify some of the issues which I believe need to be addressed and discussed during the course of this symposium. I believe that the ICF program, if it is applied and enforced correctly, could have a very major impact in reforming our institutions and in supporting the development of intensive programming facilities at the community level. Whether or not this promise is realized depends on you and on me as much as it does on HEW, the states and the facilities themselves.

See Appendix A
for listing of
Regional HEW Long-Term
Care directors

QUESTION:

Can the regulations accommodate handicapped and non-handicapped people living under the same roof?

RESPONSE:

The regulations permit it to a certain degree, but with a price. For example, a facility may well have a diverse group of residents, some of whom require intermediate care, some of whom require skilled nursing care, some of whom are physically handicapped, some of whom are not. It's perfectly permissible for all of these individuals to be living together under one roof. The price you pay is that that facility will be required to meet all kinds of different regulations to cover the needs of all those different people. Even one physically disabled person, for example, and the facility has to meet all of the ANSI standards to make the facility barrier-free. You will also get into problems with the Life Safety Code where, because of one physically handicapped resident, the facility will have to meet the institutional occupancy sections of the Code and so forth. It is possible to do, but it becomes costly and the flexibility is lost. To a certain degree, I don't know how the Federal Government can build that flexibility in at the present time given the present approach to regulating, which is a cookbook sort of approach. This is, you have to have certain ingredients in place, rather than looking at the effect of those ingredients on an individual person living in that environment. The regulations are not "output" measures.

QUESTION:

Is it permissible to group children and adults together in an ICF/MR?

RESPONSE:

There is nothing, again, in either the intermediate care or the skilled nursing facility regulations which would prohibit that, except that the facility would have to provide the kinds of services, the life environment

which meets the needs of both children and adults. Those needs are going to be somewhat different. The standards of the Accreditation Council, which have been incorporated in a somewhat revised form in the intermediate care facility regulations, do talk in general terms about groups of persons together - you're probably familiar with that - but there's no outright prohibition.

QUESTION:

Why is there a difference between skilled nursing home payment and ICF payment?

RESPONSE:

For those of you who aren't familiar with the issue, let me just take a minute to outline it for you. When the Congress added intermediate care facilities to the Medicaid program, they did it partially because they saw ICF's as a lower cost alternative to skilled nursing care. As a result, they required in the law that the state had to establish a differential in its reimbursement rates for skilled nursing facilities and intermediate care facilities. Many people have felt that the intermediate care facility of any sort, but particularly an intermediate care designed for retarded persons, doesn't provide a less expensive (than skilled nursing care) kind of care - it just provides a different kind of care. HEW, therefore, published regulations which said that intermediate care facilities did not have to be reimbursed in accordance with the differential established for skilled nursing facilities, and it is my understanding that this regulation applies to all intermediate care facilities which are classified as ICF/MR's.

QUESTION:

Can an ICF program be funded if it's in a facility that is not an ICF facility?

RESPONSE:

Yes, the regulations do permit that. But, they put certain requirements on a facility which does that. Whether you have an intermediate care facility unit, for want of a better word, within a larger institution which is not an ICF, HEW refers to that unit as a distinct part and that distinct part must meet each and every one of these ICF regulations standing alone. In other words, if the ICF unit is not administered by

a qualified mental retardation professional but the larger institution is, it probably would not be acceptable to HEW. But so long as that distinct part meets all of the ICF regulations, it is permitted. In addition, another requirement is that the state must have a policy permitting such distinct parts to be certified.

The "distinct part" policy has caused a problem in some instances where the large institution, a state school, for example, which is pretty dismal, which can't meet the ICF regulations, establishes one small part as an ICF. They rob Peter to pay Paul - they take the institution's staff and concentrate it all in the small distinct part unit. That unit gets accredited. Whether the staff remains there after accreditation is anybody's guess. Even where they do, there are many people who feel that the distinct part policy, as part of a public policy, has some very negative impacts. At the same time, though, it does provide the kind of flexibility that you raised.

The Nursing Home Setting

Henry Lynch

Besides my normal stagefright prior to speaking, I am absolutely petrified because there is no sprinkler system in this conference room. Since I do feel so threatened, I must tell you the truth, a deathbed confession, so to speak.



Mrs. Elkin had originally asked me to speak for 15 minutes. Last evening, I arrived around 10:00 p.m. and ate a late dinner. Unfortunately, the other speaker on this topic is unable to attend, and I learned of this fact for the first time after dinner. Mrs. Elkin calmly requested me to extend the scope of my talk to fill approximately 45 minutes. She was persuasive: "You are always telling me, Henry, that the solution to every problem lies in the private sector. Now, prove it." She calmly assured me that I could be prepared by 10:00 a.m. this morning. Dazed, I left to register for my room and to begin work.

At this point, I had already noticed that there were no sprinklers in the conference room, and I suspected a plot to wipe out the private sector. I refused the porter's help, just in case he was part of the plot. Since my key had "F-2240" stamped on it, I naturally looked for the 22nd floor. Anyhow, somehow, I became lost for at least 45 minutes in this confusing, circular design of rooms and floors.

I felt controlled by the environment. I felt like a little steel ball in one of those children's games where somebody keeps twisting the game board until the little ball becomes lodged in the nose of some ghoulish face. Eventually, I found a telephone. Reassured of some control of my environment, I fought back feebly. I called HEW to obtain a grant to find Room "F-2240." I proposed a 10% indirect cost, a 230% cost for demographic distribution analysis and an 8% fee for evaluation and dissemination. Fortunately, a kindly gentleman named Ford answered the telephone and mentioned that a previous research grant by NARC had located a similar room on the second floor.

I found my room at last and started to question the reason for the design of the building. It had controlled me. In my anxiety over this presentation and compounded by separation from my normal environment, I concluded that the building was designed to ensure the necessity of a porter directing a guest to his or her room. My interpretation of the "building statement," at least last night, was: "Tip the porter, or else!"

Then, I became angry. What is the "building statement" made by our "nursing homes?" One hypothesis that a retarded person living in a "nursing home" would adopt: "All retarded people living in such an environment must be totally dependent because of the protective building design." Our reply, ladies and gentlemen, based on the present populations of "certified nursing homes," should be a loud "no" in most cases and strong agreement in other instances.


*Jenney is a six-year old person.... She
 is more than an abstract collection of
 "assessment areas"....*


Society needs regulations, and retarded people need to live in a safe environment, but let's make certain that - as a result of this conference - we don't lose sight of individual people in our obsession with regulations and federal money. The ICF/MR regulations and the Life Safety Code are necessary, but let's not inflict an unsuitable, overly protective environment on individuals simply because of a money stream. Don't soothe your conscience with the balm that ICF/MR regulations at least "assure program." My irreverent reply: An individual program plan

is a piece of paper, not a person. A piece of paper is kept on file. A retarded person lives, and should be allowed to live and learn in the least restrictive environment that allows dignity and safety. A retarded person should not feel like a little steel ball, twisted aimlessly in a child's game, under glass, controlled by our good intentions, looking without control for a hole we have predetermined to be his niche. In summary, and with anger rather than humor, be certain that we are not inflicting an overly controlling regulation and building on retarded people solely because money is available.

Let's talk about a dependent, retarded person who does need a structured, protective environment. Mrs. Elkin is passing around a photo of a child in our Home whom I will call Jenny. That is not her real name. None of you know her or her family. She has, as you can see, severe hydrocephalus with a 33 inch head. She is blind, somewhat spastic in all four limbs, and suffers from petit mal seizures as well as from dwarfism. Jenny is, however, a six-year old person, more than a collection of abstracted, separate "assessment areas" that can be accurately reflected on a piece of paper in an individual program plan. Allow me a personal comment. Our professional staff and their refined assessment scales can measure Jenny's progress since birth, but no one yet has explained why she thrives despite her massive handicaps. I don't believe that anyone's assessment scales are accurate or sensitive enough yet to measure the intelligence of such children, if we define intelligence broadly as the ability to solve problems in our environment. Our Program Director wrote a behavior modification study on Jenny and - honestly - concluded that his behavior was modified, not hers.

I assume that Jenny needs "nursing home" care as defined under either the Federal Intermediate Care or Skilled Nursing Care regulations. We recently fought a battle with the social service agency which pays Jenny's fee to prevent just such a move. That agency would have been able to "draw down" federal dollars if Jenny were in a geriatric nursing home certified to provide skilled nursing care under Federal regulations. In our state we have not yet written skilled nursing regulations applicable to mentally retarded persons that also meet Federal guidelines. The Federal, geriatric regulations apply in the meantime. The transfer to a geriatric facility, in my opinion, would almost certainly have been inappropriate for Jenny. Outside agencies also agreed. To the social service agency's credit, it did not move Jenny. But I question if other agencies throughout the country will have the courage or money to make similar people-oriented decisions.

people oriented
decisions

Let me continue with Jenny. The most important part of her life is her "home" and her "family." While I don't believe that some of her likes and dislikes should be encouraged, she is so sensitive to her environment that she often refuses food from new staff. Most children at this low level of functioning are so impaired in other ways that their sensitivity to the environment assumes a heightened importance. Would this child have survived an abrupt transfer, made solely on the basis of money? Perhaps - She is extremely aggressive. But how many people have this little girl's zest for life?

people who
need people

I am not criticizing the Life Safety Code, the ICF/MR or SNF regulations. However, even assuming individual program plans, we must remember that retarded people are individuals, and that regulations and federal dollars that allow a 1975 version of congregate care might not be the appropriate answer for retarded people truly dependent on others for the highly structured but individualized, habilitative environment that a residential placement should offer. Abrupt transfers to "certified nursing homes" can be disastrous. Like it or not, we are here to discuss the "dumping" of people in nursing homes because of the availability of a new funding stream.

Incidentally, should a nursing home be only a physical plan that meets Chapter X of the Life Safety Code of 1967? Might not a dispersal of apartments throughout a complex - with a registered nurse immediately available - meet individual nursing and safety needs? Wouldn't such an arrangement allow increased evacuation time in case of fire? Wouldn't such an arrangement also meet the spirit, if not the letter, of Chapter X of the Life Safety Code? Can't safety be achieved without the enormous expense of new construction for "institutional" and sterile physical plants?

a nursing
home setting

With some of my previous thoughts as background, let me try to define informally a nursing home setting, as I see it.

"In an appropriate and safe physical environment, under responsible and accountable management, monitored by parents, private advocates and governmental agencies, it is the gathering of appropriate professionals, non-professionals and volunteers for the purpose of providing various opportunities for development to highly dependent retarded people. Because of either already existing or potentially extensive health limitations of the retarded people, the service must be health-care oriented as well. There must be a linkage and a tension between the

appropriate risk needed for development and appropriate precautions resulting from health limitations. Just as importantly, the setting provides a home for the period of time when the retarded person is too dependent for other living arrangements."

Keep this definition in mind. Let's assume the continued existence of ICF/MR regulations, Skilled Nursing regulations and Chapter X of the Life Safety Code. Let's assume that we will more accurately and narrowly define the population who truly needs the highly structured and protective service to which these regulations were intended to apply. I stress that I am referring to client needs, not available money streams, or available "bed-space," whatever that is. I propose a continuum of service to reflect the subtle needs of these retarded people. This is intended only as one person's reflections on subtle differentiations of individual needs, and it is presented primarily to provoke thought.

a continuum
of services

LEVEL 1 - EXTENSIVE MEDICAL INTERVENTION

It is defensible but not necessarily preferable that this small "home" be located in a hospital with staff aware of developmental needs as well. These retarded people need life-maintaining medical services predominantly, perhaps over a long period of time. Such a person might need tube-feeding, aspiration and have a high susceptibility to upper respiratory infection because of immobility. The developmental or educational needs of these people are less immediate, but should not be neglected. For example, physical therapy can possibly prevent contractures in unused limbs that, if allowed to occur, would later hinder a person's development.

LEVEL 2 - SPECIFIC MEDICAL INTERVENTION

The medical involvement necessary for a person in this "home" will be a great deal less than for a person in a Level 1 "home." Perhaps because of a heart defect or an uncorrected swallowing problem necessitating tube-feeding, these people need the direct services of a nurse and physician, but their developmental program can be more active and regular than for those people in Level 1.

LEVEL 3 - TOTAL CARE

These retarded people need health supervision from a registered nurse and physician, but total dependence for basic needs can be met by para-professionals and by professionals from other disciplines. Development of self-help skills would presumably be the primary need of this population. Because of their total dependence, probably non-mobility and resultant high susceptibility to upper respiratory infection, daily supervision - not necessarily direct care - by a registered nurse is important for these retarded people.

LEVEL 4 - PHYSICALLY HANDICAPPED

People in this home will have a higher functioning ability, extensive self-help skills, but will be unable to exit on their own power in case of fire. These retarded people may vary widely in ability, and I am honestly beyond my experience in hypothesizing this single grouping. Conceivably, many sub-groupings fall under this "Level 4." I am simply pointing out the subtle and not so subtle differentiations among the retarded people covered by the same Chapter X of the Life Safety Code. We provider, regulators and advocates must remain sensitive to individual needs to prevent inappropriate placement.

Please allow me to add a few more thoughts before summarizing the presentation and answering questions.

staff
expectations

The nomenclature "nursing home" itself is hideous. I like the idea of "home," but the linkage with geriatric concepts that the term evokes - and thus the unquestioned acceptance of the appropriateness of the linkage in most people's minds - is dangerous. Retarded people have enough problems without being subjected to the many problems of the geriatric service model. Most importantly, I believe service in a geriatric nursing home demands a staff motivation different from staff motivation in a home for retarded persons.

Let me also depart from some standard beliefs, such as, "Because of the expense involved, it is necessary to provide this service in a large setting to save administrative overhead." Financially speaking, I challenge anyone to prove that a large setting is inherently less expensive than a small setting - assuming capable, client-oriented management in both situations. However, I hasten to add that "client-centered management" is the key to quality of service and not the size of the facility, per se.

Incidentally, I feel very strongly that "developmental nursing" service, as I like to call it, should be monitored closely by parents and private advocates. After all, the concept that governs the provision of highly structured residential service should be "the least restrictive alternative" for the client. It is the function of the parent or advocate to make certain that the needs of the client are met before the needs of the provider agency. It is also a function of the provider agency, with parents and advocate groups, to make certain that clients' needs are met before needs of governmental placement or regulatory agencies. There is a necessary, but healthy, tension in all of these relationships, especially if retarded people are to progress appropriately along a continuum of service. The phenomenon of "dumping" as a perversion of the concept of deinstitutionalization would not have taken place so widely if parents and advocate groups had been more effective.

least restrictive
alternatives

Finally, in the question of placement of highly-dependent children with highly dependent adults, I personally feel that the children should be separated from adults. From what I've experienced, adults at the same functioning level tend to be neglected in favor of the children who are somehow "cuter." I am not totally convinced about the accuracy of this assertion, but I would prefer to administer separate homes for children and adults. Again, it seems to be a question of different staff motivation for a somewhat different service.

I'd like to reiterate major points. Be sensitive to "building statements." As beautiful as this hotel is, you probably wouldn't want to live here every day. It is not a home. Retarded people who live in an out-of-home setting still need a home. They are sensitive, human beings first, handicapped and/or health-impaired secondly. For the sake of administrative convenience, and a money stream, let's not lump retarded people into one category and provide a 1975 version of congregate care in a safe building. Instead, I propose, for those retarded persons who are truly dependent, a continuum of service based on a developmental-medical model in which there is tension between the risk needed to encourage development and the precautions necessary because of health problems. I personally prefer small, geographically separate homes because residential service management, and by that I mean the utilization of people and money to meet the individualized needs of retarded people in a sensitive way, is much more easily accomplished in small homes. This is a personal preference. Monitored, client-centered management is the key, regardless of the size of the "home."

client-
centered
management

Should these units be in a hospital? I personally prefer not, because retarded people will inevitably be perceived as patients. Should these units be in wings of geriatric nursing homes? I strongly oppose this concept, but let's admit that probably somewhere in the country, or in many locations throughout the country, there are units in large institutions, in geriatric facilities and in wings of hospitals, that may be operated very sensitively for the people they are trying to serve, probably because they recognize some of the problems I've stated, possibly because they know more about the problems than I do. I want to be careful. I have seen too much division over management models. Let's be careful that we advocates, regulators and conceptualizers do not treat the people who are providing services insensitively when we demand, and have a right to demand, that they treat retarded people sensitively.

QUESTION:

What about the right to education of retarded persons who may be residing in a nursing home setting?

RESPONSE:

In September, 1972, the consent decree went into effect in Pennsylvania guaranteeing every retarded person, regardless of the degree of handicap, access to an "appropriate" public school education. Some of our children have been able to attend classes in the community. We have had specially trained teachers for the children who must remain in the facility because of excessive risks associated with daily transportation. Our staff has worked cooperatively with the public school teachers. We have our own preschool program, funded under the Department of Education, and we have been able, formally and informally, to dovetail the programs, not so that they are the same by any means, but so that we are talking cooperatively about a continuum of service and common goals. The Montgomery County Intermediate Unit (the

county special education unit which provides services to children with special problems requiring specialized staff not available in the local school district) has been most cooperative. Unfortunately, the school code does not yet allow a 12-month program for our children. I believe that must eventually be a responsibility of the educational system.

QUESTION:

Aren't there sometimes advantages to mixing age groups and types of handicaps?

RESPONSE:

In terms of children and adults, I think it can be done. I think it depends on the leadership you're giving to the people who are providing the service. I think it's more difficult to mix children and adults, as I said before. I think that the children tend to get more of the attention or be preferred to the adults who are not as "cute." But mixing of children and adults can be done. I feel strongly that as much as possible we shouldn't preclude options for people, and we should not preclude creativity. Retarded people need our creativity, as little as we have.

I think Dr. Boggs may have been referring to a program, I think it's in Iowa, where a facility has mixed the more disabled with the less disabled even though they weren't supposed to do so and have tested it out by going and pulling the fire alarm. They found that these people got out quite rapidly because the ambulatory people simply picked up the non-ambulatory persons and carried them out and their evacuation time was brief. Actually they were much safer than in the buildings where they had all of the non-ambulatory people and had to have nurses get them out because they just didn't have that many people.

QUESTION:

Who are the mentally retarded people who need health services?

RESPONSE:

I'm sorry that's unclear. Every retarded person needs health services, obviously. I was talking about intensive attention, really 24-hour-a-day nursing care. I can tell you some of the processes I'm

thinking about: tracheotomy care, tube-feeding, regular nasopharyngeal aspiration. Children with serious seizure problems, serious heart defects, children with tracheotomies that can't be closed for some reason. These are the "Level 1" people I referred to, and they are a very small percentage of retarded people. Does that clarify?

(From the audience) Yes. I guess your view of health care services and mine are quite different and that's why I was curious to know what precisely you were saying. I think for many of us health services are very broad and health care is very broad, and it's not the same thing as treatment for illnesses.

(Mr. Lynch) Sure, I agree. I feel that health service in that case is very broad and is secondary to the developmental needs of the retarded. In the cases that I'm concentrating on, it's primary or at least equal to the developmental needs. That's how I'm using the concept. The major point of my presentation was that very few people appropriately need this highly protective service.

Appropriateness of Nursing Home Settings

James Clements

I haven't come here today to report the miraculous discovery of a perfect alternative to institutional placement of mentally retarded people. But I have come here today to discuss institutionalization of the mentally retarded because, indeed, placement of the mentally retarded outside their natural homes into any living arrangement not of their own choice is institutionalization.

By definition, an institution is a disposition, arrangement or an establishment. To institutionalize means to make a disposition or an arrangement. For those mentally retarded people for whom nursing homes are generally being utilized, a disposition is being made for them and not by them. An arrangement is being made for them and not by them. They are being placed in the nursing home establishment not of their own accord but by the decisions of others.

institutionalization

Precisely, Webster's dictionary defines a nursing home as a residence equipped and staffed to provide care for the infirm, the chronically ill and the disabled. Or, if one is in England, it's known as a small private hospital. I would wonder how many of our retarded citizens accurately fall within the intent of this definition, and I would suspect only a very small percentage would. I suppose all of us here today are somewhat schizophrenic in our ideologies. In this

deinstitution-
alization

era of economic deprivation we have to become fiscal pragmatists. Philosophically, most of us have embraced a concept of deinstitutionalization which, as you know, is a federally-coined term used to characterize one of the mental retardation goals expressed by President Nixon in 1971. The goal was, in essence, to reduce by one-third nationally, the census of the state-operated mental retardation institutions; one-third being the estimate of the number of residents who were inappropriately placed in state mental retardation facilities. I suppose my question here is, are we proposing to relocate this one-third to private institutions? Actually we are not, as the largest nursing homes in this country are what we formerly called state mental retardation institutions. Yes, the old state-operated, multipurpose institution for the mentally retarded. I wonder, is it better to call them "skilled nursing" facilities or "intermediate care" facilities for the mentally retarded? Well, at least we have two options now... the state-operated nursing home and the private nursing home. Is there a difference from the former system? Yes, I think there is one major and rather magnificent difference and that is the federal dollar.

endless
humiliation
and fear

In the 1950's a movie entitled, "The Snake Pit," depicting conditions in a state institution, shocked the nation, and I think brought rather dramatically to our attention the general, and I would say almost universal, conditions in state-operated institutions. The Willowbrooks and the Partlows have reinforced this concept. It is interesting to note a headline and an article in the New York Times on Monday, August 5, 1974, which states, and I quote, "Proprietary homes intended to rehabilitate released mental patients called the State's new 'Snake Pit'." It goes further to say that mental patients released from state institutions and placed in hotel-sized, at least they didn't say warehouses, hotel-sized nursing homes are entitled to \$5 weekly allowance from the \$375 monthly government check which they sign over to the home. But over and over again in many of these homes they are cheated of this allowance. When they complain, they are told that they were paid, often with some pointed reference to their mental state, such as "You don't remember?" To many mental health administrators, legislators, law enforcement officers and community leaders this is symptomatic of what many of them consider the new human "Snake Pit," that had moved from state mental institutions to flourishing proprietary homes.

The depressing atmosphere of these homes subsidized by public funds in the name of rehabilitation, is one result of what critics of the homes called the "icy indifference" of the operators toward the residents. They say the result is endless humiliation and fear. They are rarely

capable of supplying the special needs of the mentally retarded which range from reading to toilet training. A Federal official said yesterday that "although all state mental health agencies are supposed to review treatment received by mental patients released to private facilities, the government has not received one complaint about such private institutions from any state in the nation." "The truth is," says Police Officer Michael McDonald, "these people have become zombies, and I would ask you, can zombies complain?"

can zombies
complain?

My personal knowledge of several situations is: In one nursing home mentally retarded ambulatory residents were tied into nylon net laundry bags at night to keep them in bed. A toileting accident during the night sentenced the person to remaining in the same condition for the following day; in another nursing home covered cribs were used to keep ambulatory children in bed. The siderails were secured by locks and chains; a third nursing home tied non-ambulatory and young ambulatory individuals, spread-eagle, in bed to ensure that they did not get up in the night and wander around. And I would ask you, can any of you distinguish which nursing home described is private and which is state-operated? Remember, when we are talking about nursing homes, we are talking about both proprietary and state-operated. I am told that some are good, some are bad. We are still, however, talking about an institutional system.

an institutional
system

What about medical considerations for placement? Medical reasons for admission of the mentally retarded to nursing homes should be the same as for anyone else - a physical debilitation injury or illness requiring a level of medical nursing care of less intensity than a hospital but of greater intensity than that which can generally be managed or provided in one's home.

Despite my earlier statements, there can be appropriate use of nursing homes for mentally retarded people. The nursing home placement should be related to certain criteria...making this placement the treatment of choice. Such factors as simply moving an individual out of a state-operated institution, or availability of federal funds, are not legitimate medical reasons for placement. What are some of these medical reasons for placement? One that I would consider is overwhelming, unmet medical and nursing needs. The family and the physician are rarely confronted with a mentally retarded individual who requires constant medical and skilled nursing care for the maintenance of life. Exceptions, of course, do occur. Examples are certain devastating congenital anomalies such as the irreparable, open meningocele,

the treatment
of choice

health
problems

the retarded person who is a victim of severe injuries or the elderly retarded stroke victim. Following the period of hospitalization for the acute phase, the convalescence in a less medically intense environment such as a nursing home may be indicated for an appropriate period. Another indication that I would consider medically necessary would be indepth diagnosis and evaluation and a trial of therapy. Some mentally retarded persons need a more elaborate and prolonged diagnosis and evaluation than is generally available in certain communities. It is impractical for most families to accompany their retarded family member to a distant city for days or for weeks for this type of elaborate workup and trial of therapy. In some instances a trial of therapy under careful observation is necessary. Adjustments and re-evaluation may be necessary before a home treatment program can reasonably be handled with ease and with success.

behavior
problems

A third indication is sudden, severe and unexpected regression in the behavior or physical condition of the retarded person. During periods of family stress or during periods of relative inactivity in community programs in which the mentally retarded person has been participating, he may react with behavior incompatible with home or community activities. Wisely and carefully chosen temporary removal may, and I do emphasize may, provide a settling or stabilizing effect which can add immeasurably to the pleasurable and profitable return of the retarded person to family and community. A premature or post-mature decision in these situations could conversely precipitate a permanent breach from the family and the community. The sudden and drastic physical deterioration in the condition of the retarded person might be, of course, managed in a similar fashion.

A fourth indication is the mentally retarded person who is progressively deteriorating, with certain metabolic disorders and particularly with progressively degenerative diseases of the central or peripheral nervous system. Placement of a person outside of the home setting is almost inevitable at some point in the course of the disease. This is, of course, especially true in those conditions of long duration.

multiple
handicaps

Another indication might be the multiply orthopedically handicapped, retarded person. Non-ambulation, especially in the young and physically small, multiply orthopedically handicapped person is not an indication for placement in a state or in a private nursing home.

Serious feeding difficulties, difficult to manage medical emergencies and increasing physical size may preclude successful home management and

require consideration of the nursing home as an alternative to home living. The non-ambulatory young child, uncomplicated by other problems, does not, however, constitute an unmanageable home problem. The previously delineated problems and/or conditions, in my opinion, relate more to the category of skilled nursing facilities than to the so-called intermediate care facility for the mentally retarded. Actually, of those conditions that I have just discussed, one could remove the criteria of mental retardation and the medical indication would still be valid. This applies as well to the general population. If one uses adequate and precise criteria for admission to skilled nursing facilities, I am not sure that one could justify separate skilled nursing facilities for the mentally retarded just on the basis of mental retardation. Indeed, if one examines the skilled versus the ICF/MR, the skilled facility will be more restrictive but less costly than the ICF/MR, a fact that HEW apparently has recognized by a regulation change on April 1 of this year.

criteria for
admission

Are there medical considerations for the use of ICF/MR's? In and of itself, my answer is categorically no. The facts are that the placements, in this instance, are generally made on the basis of social and financial, rather than medical, consideration; family needs rather than the needs of the retarded person; community needs rather than the needs of the retarded person; the availability of federal assistance rather than necessarily the needs of the retarded person.

I don't intend to imply that these are frivolous or unnecessary considerations. I simply mean, or want to say, that these are not medical indications for placement. We have become opportunists in using available federal funds in combination with the current fad of deinstitutionalization. The concept of deinstitutionalization is a valid one which is, unfortunately, rapidly being corrupted. The original concept was in essence bi-fold: 1) Prevent unnecessary institutionalization; and 2) remove those individuals currently inappropriately placed in institutions to more appropriate settings. As I remarked earlier, we have corrupted this in some instances to mean: 1) Change existing institutions to nursing homes; and 2) use proprietary nursing homes as institutions.

opportunism
and the federal
dollar

Let's take a look for a moment at the state-operated, institutional nursing homes. Why have we now converted them to nursing homes? The reason is simple and is financially logical - to get additional sources of revenue - to use federal dollars in lieu of state dollars.

fiscal
bonanza
or fiscal
folly?

Hopefully, with the new ICF/MR guidelines, improvements will occur along with the change in name. When one recognizes that there are probably less than 200 evaluators of nursing homes with any degree of training in application of the ICF/MR guidelines, hope for real improvement at the moment is dim. If an estimated cost of 45 to 50 dollars per day to meet these guidelines, if enforced, is required, and a severe limitation is placed by most states on payment to proprietary nursing homes, what private nursing home operator can afford to provide services to the mentally retarded? The state-operated facilities will have to spend many millions of dollars, in addition to increased operating costs, on physical renovation. A hoped-for fiscal bonanza might become a fiscal folly. The question may boil down simply to whether we deplete the federal and state treasuries, or do we provide less than what is currently thought to be necessary for the proper habilitation for the retarded.

Back to the indications being used for placement in proprietary ICF/MRs.

indications
for placement

- **DECOMPRESSING THE INSTITUTIONS.** This is rather obvious, but unless the ICF/MR guidelines are rigidly and correctly interpreted, monitored and enforced, we are simply substituting a privately-operated institutional system for a state-operated one. If both are properly operated, monitored and regulations and/or guidelines enforced, I frankly don't see the practical difference.
- **THE PROFOUNDLY RETARDED, AMBULATORY INDIVIDUAL.** A profoundly retarded individual, particularly one who is hyperactive and incapable of relating to, or participating socially with, others almost always, at some point during his life, may require placement in an alternative living situation. The properly operated ICF/MR could be an appropriate alternative.
- **THE SEVERELY RETARDED AMBULATORY PERSON.** In the absence of obstreperous and destructive behavior, unusual and unmet medical needs and special family problems, the severely retarded child could reasonably be expected to remain at home during the early years of life. It should be remembered, however, that as this child grows older the problems will increase with increase in body size. If the family unity dissolves with age or death of the parents, the journey to the ICF/MR becomes more clearly defined and in the minds of some, a suitable placement.
- **THE MODERATELY RETARDED, SEMI-DEPENDENT INDIVIDUAL.** One would not argue that as long as the community and home and supervision are available these individuals are served with relative ease. The deterioration of a family group, or in the event that overt, unacceptable

behavior occurs but cannot be controlled with reasonable treatment, and foster care cannot be obtained and group homes are not available, what are your alternatives?

- **THE INADEQUATE HOME SETTING.** Some families, for many reasons, find home care for the mentally retarded an entirely unsatisfactory situation - when overriding emotional problems of the sibling occur, the necessity for both parents to work outside the home, or social or financial problems interfere with adequate home care, temporary, or permanent, placement of the retarded individual outside the home may be necessary. Despite this, inept placement might well prove to be far more harmful to all parties involved than the problems leading to this placement. And I ask you, are we providing a convenient misplacement in the ICF/MR nursing home institution?
- **THE RETARDED OFFENDER.** For those individuals with delinquent behavior or those in serious criminal or legal difficulties, will the ICF/MR become the logical placement? I contend that the competent mentally retarded person who is an offender has the same rights to due process that you and I have. All too often the diagnosis of mental retardation restricts the retarded person from this normalizing process and results in a non-adjudicated lack of due process life sentence. Will the proprietary ICF/MR become the usual repository as the state institutions have been in the past?
- **THE ABSENCE OF LESS RESTRICTIVE ALTERNATIVES.** When one considers that to close Willowbrook one would need 300-plus group homes, or approximately 1,500 foster homes, or a combination of these alternatives; or to close all the public residential facilities in the United States, approximately 30,000 group homes or over 150,000 foster homes would be needed simply as a start, one can readily conceive the burgeoning growth of the ICF/MR mega industry. I am not sure that this is what Congress really intended.
- **HABILITATIVE CONSIDERATIONS.** During November of 1974, the Accreditation Council for Facilities for the Mentally Retarded of the Joint Commission on Accreditation of Hospitals published a definition of habilitation. It is defined as a process by which the staff of the facility assist the resident to acquire and maintain those life skills which enable him to cope more effectively and efficiently with the demands of his own person and of his environment and to raise the level of his physical, mental and social efficiency. They went on to say that habilitation includes, but is not limited to, programs of formal structured education and treatment.

right to
habilitation

The American Association on Mental Deficiency in April, 1975, published a draft statement entitled, "On the Right to Habilitation for Persons Who Are Mentally Retarded." Certain rights of the retarded individual to habilitative services were included in this statement, and some of these rights are:

- The right to a free public education;
- The right to quality medical care;
- The right, in accordance with written individualized habilitation program plans, to such training and habilitation, therapeutic and counseling services as will assist the individual to develop his or her maximum potential;
- The right to engage in productive labor;
- The right to assistance in securing access to appropriate services and exercising his or her full rights as citizens;
- The right of the individual to exercise freedom of choice in the selection of services;
- The right to a physical and social environment conducive to the development and growth of the individual and the full exercise of the other rights listed.

This draft statement further denotes certain elements needed for effective habilitation, and these include compensatory rights. Retarded individuals should be entitled to receive specialized adaptations of existing services which are designed to assist them in exercising their full citizenship rights and privileges. Some of these services should be as close to the accepted norms of society as possible; offered in as normal a physical setting as possible; employ intervention techniques which minimize the degree of infringement on the individual client's rights and privileges without restricting or sacrificing the prospect of positive goal-oriented results; to provide an appropriate balance between changes in environment and alterations in behavior.

habilitation
plan

And a second major element of this was an individualized habilitation plan, which was described to you earlier. Now, you might be interested, speaking of the individualized habilitation program plan, in what I found on a recent visit to a certified ICF/MR. In reviewing records I chose the two best individualized program plans that I found, and I'm quoting exactly from the records.

Treatment Plan #1 - Short-term goals: Speech and hearing, independence, preventing injury. Method: Dressing, bathing, toileting and safe environment. Long-term goal: Prevent stasis edema, increase socialization. Method: Good nursing care, foster grandparents, sewing and cooking class, transfer to appropriate ward. Long-term goal (and this is psychological): Improvement of self-help. Method: Goal planning, shaping, backward chaining. Treatment plan: Social services. Short-term goal: Bathe herself independently, completely dress herself including left shoe and sock. Short-term goal: Nursing, prevent stasis edema and increase socialization; has foster grandparent; increase interaction with others; developmental dexterity; self-esteem; safe environment. Method: Foot stool; foot elevated; is involved with foster grandparent; goes to cooking class; supervision in safe environment to prevent injury. Long-term goal: Independence in dressing, bathing, toileting, transfer to more appropriate environment.

Treatment Plan #2 - Speech and hearing. Short-term goal: Decrease hyperactivity. Method: Daily recreation with foster grandparents. Long-term goal: Maintain present health service. Method: Medicine given properly, keep bowels open, good skin care. And the monthly summary as required: Has been resting well at night; still quite active in the dining area, slides chairs all over floor area to get close to other residents in order to rip strings off their gowns. Just loves to sit and play with strings.

In a recent paper entitled, "Alternatives to Institutionalization," Philip Roos outlined several foci of dissatisfaction with current institutional services. Certain of these are dehumanizing conditions, such as regimentation, false idleness, control both chemical and physical, and negative environments. Others were unsanitary and hazardous conditions, lack of habilitation contributing to aggression and deterioration, self-containment and isolation, exploitation of residents.

dehumanizing
conditions

State-operated and proprietary nursing homes can be dehumanizing. Idleness, by my observation, is the rule rather than the exception. Control, seclusion and restraint are not uncommon; use of psychopharmacologic drugs, that is tranquilizers, range, in my observation, from 28 to 70 per cent in this country. In a group home I visited in Denmark for the mildly retarded, 71 per cent of the residents were on tranquilizers.

negative
environments

Negative environments - the majority of the nursing homes, unfortunately, those that I have seen, are still operated on the hospital model. The hospital-like tile and terrazzo environment is still not uncommon. Isolation - unfortunately many abandoned school buildings, particularly in the South and particularly in small, isolated communities, have been converted to nursing homes. Well, I guess I could go on and on, and I regret to report that I have not seen an ICF/MR that I would consider one that truly offers a complete program of habilitation that is documented by precise developmental data.

I would now like to spend a brief time telling you about a personal experience utilizing proprietary nursing homes as an alternative to institutionalization. In 1973, we made a survey concerning possibilities of placement of retarded individuals in nursing homes in Georgia, and we contacted the Georgia Nursing Home Association for their recommendations about the best homes to use. We set up a contract with them spelling out certain provisions which must be provided by both the Georgia Retardation Center and the nursing home, and provisions for monitoring the nursing homes to see that the provisions were, in fact, being provided. This was on the basis of the pilot placement program and originally confined to two nursing homes, and a period of six months was decided as a trial period. The staff from the nursing home came to the Georgia Retardation Center to see the students proposed for placement. The nursing home staff was given an opportunity to reject any student they felt they could not manage. Supervisors, nursing staff and direct care staff were given a training program which involved each discipline that had been working with the student. They were instructed on what each was trying to do for the student, the goals of this program and the treatment or management techniques utilized. Refresher courses were offered as staff changed or as specific problems arose indicating that more training was needed.

a pilot
placement
program

A team from the Georgia Retardation Center was responsible for making and monitoring the placements. This team consisted of a social worker, a nurse, a physician and a records librarian. Each family who had a student proposed for nursing home placement was contacted to explain to them the services to be offered by the nursing homes. The planned monitoring and the continuance of the student program were outlined to the family. Each family was given time to visit the nursing home where the student was scheduled to go and decide for themselves if they wished the placement to go forward. All adaptive equipment being utilized by the student, that is, wheelchairs, feeding devices and so forth, was sent with them. Additional equipment was supplied as needed. A two

2. The Division of Developmental Disabilities should immediately launch a nationwide program to train evaluators of nursing homes in the use of the ICF/MR guidelines.
3. The Division of Developmental Disabilities should carefully design and conduct an adequate research study to determine if their new guidelines are (a) properly enforced; and (b) if they are effective in achieving their goal of habilitation of mentally retarded people.
4. Nursing home evaluators now currently employed by the states are in a situation of almost inevitable conflict of interest. They are generally employed by agencies of state government who reap great benefits by receipt of federal funds allotted to nursing homes, particularly to state institutional nursing homes. This employment assignment should be reviewed and all possibilities of conflict-of-interest removed.

QUESTION:

Does the speaker have the same views regarding proprietary and non-proprietary facilities?

RESPONSE:

I think the same conditions could exist.

QUESTION:

What can be done about ICF surveyors who are forced by their boss to certify a facility even though it is not in compliance with regulations?

RESPONSE:

The answer to this is to complain and complain like hell. That is the only way you will ever get it done and get nursing home evaluators who

are skilled in the use of the evaluation instruments and get them out of this situation of conflict-of-interest. As you will recall, I quoted from the Times saying, "not one complaint has been made." How can HEW react if we don't complain?

In the surveyor training courses we were told very frankly by the evaluators that they were employed by the state agencies who would reap the greatest benefits from these federal funds, and if they caused a facility not to be licensed, they would lose their jobs. This is a very practical point they must face.

QUESTION:

The question is in regard to re-education. I think it is a statement of a problem regarding the surveyors coming in and only surveying the facility in regard to nursing care and not taking into account the particular needs of mentally retarded clients.

RESPONSE:

I think this is one of the major problems that we are facing. As Susan Weiss mentioned earlier, there were only five one-week workshops held for evaluators, and I think probably I said less than 200. The figure was closer to 150, who actually received any degree of training in the use of those particular guidelines. I think that you are quite correct that the evaluators are going to relate back to what they are most comfortable with and what they've been trained to do, and that is, to evaluate under the old model and that is what, indeed, is happening. They, many of them, haven't the foggiest concept of even the implications of the new guidelines. I still see 80 people sleeping in a room in a licensed ICF/MR. I still see staffing ratios of 1 to 60, or even worse, I saw one recently with no staff. Nobody showed up. Well, these are licensed ICF/MRs and all that has been looked at, and I don't know really what they are seeing when they are looking only at fire safety code and nursing plans.

QUESTION:

Who should be responsible for doing the evaluation, the licensing, the monitoring, etc?

RESPONSE:

I'm glad you asked that question because I don't know the answer. Maybe

somebody else does. We thought that in Georgia, at least, we had a counter system or at least a double check, and that there was a contract issued to supposedly a non-involved group, and back when I was having difficulties with the first nursing home that I mentioned, I went to this group to get information because they had been monitoring so well. They refused to give me any information; so I really don't know the appropriate way to do this.

QUESTION:

What did you mean when you said the mentally retarded offender has a right to the correction system?

RESPONSE:

The question relates to the mentally retarded offender, as to whether or not they should be eligible, as I put it, for services of the correction system. I'm not meaning to imply that one should take an individual and put an individual in a bad system. I am implying that we ought to do something about the correction system. I am even more importantly trying to emphasize that every person, including the mentally retarded, has a right to due process.

QUESTION:

When it comes to conflict of interest, what has been explored in the area of looking toward a commission or a department of human rights or consumer affairs rather than asking the service provider to also be the monitor of human rights?

RESPONSE:

This has been recommended a number of times. Now I personally am not aware of such a system. I would challenge ARCs to get involved in the act. Mr. Rosen says that the best system he has seen involves organized parent groups.

QUESTION:

I am concerned with the question of adjudication, especially in incompetence. We are presently devising a way of evaluating competence or incompetence. We are trying to make it a "skill" of competence.

The legal system does not. It is sort of black and white at this point in time. You have said some very good things about rights, but if a person is adjudicated incompetent, what happens to the rights? How do we deal with this issue in terms of the nursing home, in terms of the whole issue of institutionalization?

RESPONSE:

I think one of the answers, and I certainly don't intend to imply that I have many of them, but one of the answers is to specify the area of incompetence. Is it of the person? Is it part time? Is it full time? Is it a property? Or what is it that he or she is being declared incompetent of doing? I think all too often a blanket of incompetency procedure is conducted. We are, frankly, not that good at predicting these sorts of things yet. Mrs. Norley has suggested that another approach should be the education of judges.

QUESTION:

The surveyor training courses might be worthwhile, but no one benefits if they don't attend.

RESPONSE:

One additional problem relating to this, even when the states offered it free, and we did this, they sent very few evaluators other than those they were told to send by the regional office. For instance, we held it in Atlanta; the regional office sent two people.

QUESTION:

To be an evaluator you must be a physician or a nurse - medically related and non-medically trained people have not been acceptable in Pennsylvania - have not been considered. Do the regulations require medical surveyors?

RESPONSE:

There is no such regulation that I'm aware of.

COMMENT:

I do believe that there are many nurses who are not very well oriented, but we have some nurses in this room who have adopted the developmental model, both in interpretation and in terms of what they do themselves. I would hope that we would not be left with the impression that a nurse is never an appropriate surveyor.

Thank you for your careful attention despite the fact that I'm a physician.

Human and Civil Rights

J. Stanley Pottinger

I'm pleased to be here this afternoon; to have the invitation to talk with you for a little while about various aspects of our work in the Justice Department; how it may have an impact on that which NARC is engaged in; to have a chance to examine what we are doing and where we need to go.

The Civil Rights Division has been participating in litigation concerning the constitutional rights of retarded citizens since about 1971. At that time, Judge Frank Johnson, in Alabama, requested the United States to assist the Court in what you know as the Wyatt versus Stickney case, concerning the care provided to Alabama's institutionalized mentally retarded citizens. In that case we presented facts to the Court which showed the cruel and unusual punishment type of practices which existed at Partlow State School for mentally retarded persons in Tuscaloosa. We also presented to the Court the testimony of Phil Roos which was of immense value to the Court in establishing the standards necessary to implement meaningful relief in that case. That case has become the fountainhead of all constitutional law built in this particular area. We supported the constitutional right to treatment for institutionalized mentally ill and retarded citizens in that case and then we also had the honor and privilege of supporting the same constitutional principles when the case went to the Fifth Circuit Court of Appeals.

Wyatt
versus
Stickney .

office of
special
litigation

Since Wyatt, we have devoted an increasingly larger litigation effort to protect the rights of retarded citizens. This is a new program for us and is one which is not founded upon statutory law as virtually all other human rights and civil rights areas are. The reason our program is not founded on such laws is because there are no such laws. The Congress has not yet received such legislation in this area, but we believe that through some imaginative - and I say the word with trepidation - imaginative litigation tactics and strategies, we can continue to bring to bear the resources and efforts of the Justice Department in a constructive way. It's for that reason, in September of last year, we established, in the Civil Rights Division, an Office of Special Litigation to conduct litigation concerning the rights of children generally and with regard to physically and mentally handicapped persons of all ages.

right to
treatment

We are now participating as plaintiff intervener, as a party if you will, or as an amicus curiae - a friend of the court - in lawsuits to establish the right to treatment for institutionalized, mentally ill or retarded citizens. That was the Willowbrook case in which, incidentally, we just managed to obtain a consent decree; in Pennsylvania, the Pennhurst case; in Ohio, North Carolina, South Carolina, Alabama, Louisiana, Texas and Nebraska. In addition, we've filed independent actions as a plaintive concerning mental retardation institutions in the states of Maryland and Montana.

standards
of care

In our case in Louisiana, which was called Gary W. against Stewart, in case you have run into it, we are, for the first time ever, becoming involved also in the private child care industry. In that case, Louisiana has contracted with private care facilities in Texas to care for their dependent and neglected, emotionally disturbed and mentally retarded children. We have intervened in the case to assist the Court in establishing appropriate standards of care for these children, especially against the backdrop of kinds of abuses that seem to present themselves with regard to warehousing of children, assigning them to areas that are inappropriate to meet their particular needs, and, in some cases, allegations of assigning the children without keeping track of them.

More recently we participated in the negotiated settlement of Willowbrook, as I mentioned, and the Court in that case accepted a detailed brief which was suggested on the basis of the relief we have come to experience through Wyatt, with the help of people like Phil Roos. The decree provides, among other things, that Willowbrook will be gradually reduced in size to a total of 250 residents over a six-year period. The State of New York, I should also add, has shown a real admirable concern for retarded citizens in the state by agreeing to the required relief.

Willowbrook is the largest single state facility for the mentally retarded in the United States and has some of the worst problems. For those of you who are familiar with it, I think you will agree, and we think that by the significant steps the Governor and the state are now taking, the state may actually set an example for the other states to follow.

The first right to treatment case has now reached the Supreme Court. While talking to you about the development of the law in this area, you should know about O'Connor against Donaldson. The case concerns the failure of Florida to provide treatment to an involuntarily committed mentally ill person and was heard by the Court in January of this year. We did not participate directly in Donaldson with a brief but the Solicitor General of the United States did send a letter to the Supreme Court indicating, as a matter of official United States policy, our support for the right to treatment in that case. Of course, we're hopeful that the Supreme Court will define and uphold the constitutional right to treatment, and we believe that the establishment of a clearly defined, feasible, understood right to treatment as the law of the land for involuntarily institutionalized, mentally handicapped persons, including mentally retarded citizens, is likely to be accomplished soon, either in O'Connor or in another case reaching the Court.

supreme
court

Of course, improving conditions in institutions is as important, but there are related issues which I think are of equally critical importance. As you might guess, civil commitment and confinement in any institutional setting, even in one which has more desirable conditions, still constitutes a substantial denial of personal liberty, particularly where the persons involved are not accused of a crime and typically are not afforded the same procedural safeguards as persons who are accused of a crime, as criminal defendants are.

civil
commitment

The federal courts have developed a constitutional principle in response to this dilemma, that a person whose liberty has been denied pursuant to a civil process, not as punishment for the commission of an alleged crime but for some other lawful state purpose such as treatment or the protection of mentally retarded persons, that in such cases those persons must be confined in a manner which is the least restrictive of their personal liberty and commensurate with the treatment needs of the person whose liberty has been denied.

Thus, the nature and duration of confinement must bear some reasonable relationship to the purpose of such confinement. Mentally

handicapped persons whose particular conditions do not warrant the almost total restriction of personal liberty resulting from institutionalization, therefore, ought to be placed, or in some cases, must, as a matter of law, be placed in freer settings.

Now, this is not to say that all institutions are inherently evil. It is not to say that all institutions are unable to rehabilitate. Rather this development in the law is to recognize that institutionalization constitutes what we all know to be a very severe encroachment on personal liberties. Therefore, under our system of laws which holds paramount personal liberty, only those persons whose conditions truly require a loss of freedom should be so confined. State mental retardation and mental health systems are, therefore, feeling a double kind of pressure to deinstitutionalize their residents as a result of the right to treatment litigation. The first has been demonstrated in our own cases.

institutional
effect

Institutional confinement has an anti-habilitative effect on some residents with a resulting regression in their life skills. In fact, this was demonstrated quite vividly and dramatically in the course of our litigation against Willowbrook, where we were actually able to demonstrate, much to our chagrin and sorrow, that many of the residents who were there were actually in worse shape after six months to two years than they were at the time they were admitted. In addition to that, in our participation as litigating amicus in the Willowbrook case, I was directed toward demonstrating that physical, intellectual, emotional and social regressions existed in such a way that we could, in effect, convince the Court that specific kinds of relief were required. But, as I was mentioning, one response to the debilitating effects of improper institutionalization, from at least some of the institutions, has been to remove residents quite hastily.

The second pressure to deinstitutionalize stems from the relief ordered by Federal Court in the right to treatment cases which, through our own advocacy, often requires the addition of substantial numbers of staff, based upon the numbers of residents in the institution and the treatment needs of the residents.

institutional
transition

If the resident population remains static after we've won a case, court-required increases in staff logically present a substantial financial burden to the institution as compared with lowering the population of that institution so that the staff-resident ratio is better, more favorable to the residents, and, therefore, come within the realm of the law, as we have defined it in that case. So a rapid and significant drop in the

total resident population often occurs and, as a result, the pressure on the institution to deinstitutionalize its residents precipitously may be very substantial. Therefore, the possible damage to mentally retarded residents who have been conditioned over a long period of time to depend upon the institution may also be substantial if proper program support is not provided on a continuing transition basis as residents are moved out of institutions into other settings, including community-based centers.

We have recently received information about nursing homes. I should add that as a result of this problem we are attempting to build into our decrees a recognition of the nature of the problems so that the courts can take account of the problem of transition and not allow regression to occur by virtue of litigation that is designed to protect the rights of those who are in the transition.

community
placement

We have also recently received information that nursing homes and other boarding facilities, as a result of this process, are being used in several states as facilities for mentally retarded persons and may be used as an alternative to institutionalization. While these placements may often be appropriate, based upon the treatment needs of individual patients, we have a very serious concern that residents of institutions may be subjected to a dumping process where, after years of institutionalization, they are placed in facilities which are simply not capable of treating them, nor caring for them, nor habilitating them, but instead, leave them in a position to fend for themselves. We believe that the right to treatment, which we and many others have worked so hard to establish, includes the responsibility to prepare residents for non-institutional life and to provide appropriate program support after deinstitutionalization so that the mentally retarded citizens will succeed in community placements of all kinds and where the residents will be able to obtain a maximum degree of personal liberty, consistent with and designed to promote a maximum use of their human skills.

Recently, as all of you know, the conditions in the nursing home industry have been receiving widespread attention. It is attention, in our opinion, which is well merited. The information contained in the recent governmental reports and major news articles indicates that the conditions in some nursing homes may be as anti-habilitative as the conditions in some of the institutions with which we have become familiar in the course of our mental retardation litigation. Long and thoughtful consideration must be given to whether nursing homes are, in fact, appropriate placement alternatives for mentally

nursing home
industry

shocking
conditions

retarded persons. For instance, the Senate Subcommittee on Long-Term Care, in a report called, "Nursing Home Care in the United States: Failure in Public Policy," says that conditions in a substantial number of nursing homes are nothing less than shocking. The Committee report is virtually a litany of abuses in the nursing home area. Some of the common abuses that have been found and documented include negligence leading to death, intentional physical injury, poor care, poor food, unsanitary conditions, fire hazards, lack of dental care, lack of any psychiatric care, untrained and inadequate personnel, lack of activities and unnecessary and frequently unauthorized use of personal restraints. In our judgment, this kind of parade of horrors is reminiscent of the conditions we found at Partlow in Alabama some years ago and at Willowbrook more recently.

economic
pressures

A special committee on aging reported further that, "Thousands of elderly patients have been transferred from state mental institutions to nursing homes. This trend is caused partially by progressive thinking intended to reduce the patient population in large, impersonal institutions. Another powerful reason, however, may be costs. It costs the states an average of \$800 per patient, per month, to care for mental patients in state hospitals, while the same individuals can be placed in boarding homes and nursing homes at a substantially reduced cost. Charges of wholesale dumping of patients have been made in several states."

Although the special committee was referring here to the placement of mentally ill patients in nursing homes, obviously the analogy to dumping of mentally retarded residents is of equal concern to us.

GAO
survey

At the request of Congress, the Government Accounting Office (GAO) recently conducted a sample survey of nursing homes which had been certified for the Medicare and Medicaid programs. Some of you, or all of you, may be familiar with this report. When GAO reported on March 18 of this year, it said that as many as 72 per cent of the nursing homes in its sample failed to meet major fire safety code provisions which are incorporated in general Medicare and Medicaid regulations. Therefore, it appears that a substantial number of nursing homes actually constitute a danger to the lives and wellbeing of their residents.

We are aware, in the Justice Department, of the fire hazards presented by some nursing homes and are taking action to try to end this danger. On October 11th of last year, following an HEW referral, we filed a suit called "The United States against the Commonwealth of Pennsylvania," in the United States District Court in Harrisburg, to enforce the fire

safety regulations concerning skilled nursing homes which house the beneficiaries of Medicare/Medicaid programs throughout Pennsylvania. Prior to our filing suit, there had been a series of fatal fires in Pennsylvania nursing homes. It was determined that the fires resulted from violations of Medicare/Medicaid fire safety regulations. We believe that this suit, the first of its kind in the nation, should constitute a major step forward in protecting the rights of residents in nursing homes.

safety

It is also clear that persons will be removed from institutional settings and placed in less restrictive environments. We support that - we think it's a trend that is long overdue. But this change in settings for persons committed to the care of the state, does not, in our opinion, relieve the state of its legal constitutional responsibilities to protect such persons from harm, or to provide the kind of care and treatment that is designed to give residents a real chance, an honest chance to maximize their human skills and enhance their ability to cope with their environment. The state, in other words, cannot relieve itself of its constitutional obligations merely by contracting with a privately operated facility to provide the services that the state may otherwise be required to provide.

state
responsibility

Fire hazards, and other dangerous conditions that have been exposed in nursing homes, have to be remedied before they can be used as a placement alternative to existing institutions. Whether any particular non-institutional setting, including nursing homes, will comply with the constitutional treatment standards depends upon whether the basic treatment needs of each patient committed to that setting can, in fact, be met. Obviously, in our opinion, danger to one's life from fire hazards simply is not consistent with any real form of effective treatment.

Sound, effective deinstitutionalization depends upon steps taken prior to transfer, as well as those that are taken to secure fair transition after transfer. It is likely that a patient who has been confined in an institution for a substantial period of time will require assistance in preparing him to function effectively and humanly in a non-institutional setting just as he would require assistance after transfer to ensure his continued effective adjustment.

effective
adjustment

Our experience in the right to treatment cases has been that only a small number of retarded persons actually require institutionalization. It's an important number. It is a group which ought to be identified

carefully. But it is, in our judgment, and I'm sure you share it, much smaller than the present population would indicate.

normalization

The vast majority of presently institutionalized retarded persons could appropriately be placed and treated in a variety of community-based facilities. Placements of this kind ought to be consistent with the "principle of normalization." And by that, we mean that the environment must permit the individual retarded person the opportunity to function as any other non-retarded person, at least insofar as his or her own condition permits that level of freedom, that level of functioning. Therefore, if this standard is to be met, a great deal of care must be provided, or extended, in diagnosing and determining the precise nature of each individual person's needs and problems. To the extent that a nursing home may be entirely a geriatric facility, it would probably not be consistent with the principle of normalization to place a young mentally retarded person there. The persons who are available to interact with retarded persons, as in the case of non-retarded persons, ought to represent a wide spectrum of ages, abilities of interests and should include, as a minimum, a substantial number of persons of the mentally retarded person's age group.

individualized treatment

The final considerations, where the detailed standards concerning care and treatment set forth in such decisions as law, are applicable to community-based facilities in general and, of course, in nursing homes specifically. The Court in Wyatt set forth standards which included considerable detailed relief such as setting forth the exact staff-patient ratios involved in other cases, square footage per resident. Such decisions may be involved in defining the specific kind of relief that is appropriate to meet constitutional minimums in any particular case. While many of those standards that lead to this specific kind of relief may have general applicability to all facilities where retarded persons are treated, obviously, the specific relief of that case, or any case involved, ought to be measured in terms of the problems that are presented.

Different patient groups with different needs and different settings may require different kinds of staff-patient ratios and the like. Therefore, we have taken the position that the constitutional mandate in the area of the right to treatment is not the specific predetermined ratios to be met (i. e., it is not to determine the nature of relief by rules of general applicability) but rather to state forcefully, based upon constitutional concepts, that effective care and treatment must be provided. The facts of each given case will lead us through the kind of development of specific remedies, such as these we have undertaken in Wyatt, to design plans that will meet the specific needs of the residents in a particular

case. The law, in other words, must retain its traditional flexibility to permit the development of new treatment modes in the profession and, at the same time, the law must ensure that the right to personal liberty of all mentally retarded citizens is protected. For that reason the movement to protect the rights of retarded citizens is probably proceeding at a greater and increasingly greater rate in the federal government today, at least in the Justice Department, than at any other time before. The traditional practice of committing mentally retarded persons to large, impersonal institutions is under attack, and it will remain under attack.

As David Rothmund has pointed out in one of his books, institutionalization has been too seductive. Responsible officials in the government, myself included, and my colleagues and the society as a whole, have succumbed too easily to the feeling that merely keeping retarded persons behind walls will somehow do them some good. Because confinement of the patient was so easily confused with the improvement of the patient, we've allowed abuses to proliferate. Deinstitutionalization must, therefore, continue at least for all those who will benefit from it, and our vigilance must be maintained to ensure that proper care and treatment will continue to provide freer settings for retarded citizens who, by any measure of reasonableness, constitute the most helpless class of citizens in our society.

pioneering
a law

We in the Justice Department have been playing a role in this regard. It is a vigorous role. It has certain jeopardy that goes with it without statutory foundations. It has a great deal of excitement with it because we are, in effect, along with you and other interested persons, pioneering a law, the way other human rights laws have been pioneered in the past decade. So we're involved with this; we're committed to it; and we welcome your support and are proud to be a part of the effort which you are also spearheading on behalf of human rights in this country. Thank you very much.

QUESTION:

I have heard that the Wyatt versus Stickney decision has created a case against further deinstitutionalization in Alabama.

RESPONSE:

I think it's possible that it could happen, not because anyone has designed it that way, but for the reasons that I have commented on. I don't agree that it has happened yet. The concern has arisen not only with regard to Partlow, but with regard to other institutions which have come under attack, whether by the Justice Department or private litigants throughout the country. Therefore, I think we have a very strong responsibility not to rest on our laurels, so to speak, not to point to Wyatt as "the living end" of all models in this country, but rather to consider it as a pilot case which has clearly developed, in a very important way, the constitutional principles of law, but which may need to be developed further as deinstitutionalization brings on these new problems. They're not new problems, historically, but they're new in the consciousness of the law; they're new in the consciousness of government agencies. We need to be sensitive to it and not simply have some pride of authorship about the success of Wyatt.

QUESTION:

Do the gains made in the cases in Alabama and Willowbrook apply also to individuals in nursing homes? I believe you covered that very quickly, so should I assume it won't be necessary to have new litigation as a result of these cases?

RESPONSE:

Well, it has not been litigated fully, but our position in litigation is, to the extent we've touched on it, as follows: If the state, any state under the

14th Amendment, denies a person his or her liberty, there has to be a "compelling state reason or interest," as the phrase goes, for doing so. We take some of these for granted in society. If someone murders someone else, there is an obvious state interest in incarcerating the person. Incidentally, while I'm using a criminal analogy, please keep in mind that while we take that state interest for granted, we also, at the same time, extend to the defendant a great deal of procedural due process, guaranteeing to make sure that he is not incarcerated wrongly. Now we are taking the position by rough analogy that in the field of civil commitment, that is, people who have not done anything of a criminal nature to threaten society at large, the same guarantees, as a minimum, ought to be applied. They ought to at least have the same procedural guarantees as criminal defendants do. That's number one.

Number two: If the state is part and parcel of this process of incarceration which I am talking about, they cannot escape their liabilities or their responsibilities to extending these safeguards and for determining that there is a state interest in the incarceration simply because they point to a private nursing home and say, "that's private and we're the state." The 14th Amendment, by its terms, says that no state shall deny a person due process of the law, equal protection of the law, the privileges and immunities. Therefore, the 14th Amendment, which is the fountainhead of protections in this area, only applies to the state. Our position is that when the state has a part of the process by which one is incarcerated, the end result, even if it is a private nursing home, does not relieve the state of these responsibilities. Therefore, as a general conclusion, the answer is yes. The kinds of principles developed in Wyatt as to the state's responsibilities to make sure that liberty is not denied unconstitutionally would apply where nursing homes are the resulting process.

Having said all that, there is another possible scenario and that is, that a person has to engage a hypothetical model situation. A private citizen has made a private decision to enter a private nursing home. In that case, the answer is no. The 14th Amendment standards do not necessarily apply unless the state somehow has been involved in the process. The 14th Amendment, by its own terms, does not apply.

However, as all of you know, and as I understand you have been discussing, most of those nursing homes do obtain federal funds. And once they obtain federal funds, they also must understand that they

have federal strings, and the federal strings in this case, I think unlike some parts of the federal government, are well taken for the most part, and they need to be enforced better. But they are designed to make sure that private nursing homes which accept public tax dollars are not sponsoring or supporting those kinds of practices which are wrong, inhumane or otherwise dangerous. So the result is that in most cases, with a few exceptions, some federal interest will be extended to nursing home activity either through the constitutional process that is applied to state involvement or through federal money that goes to private homes.

QUESTION:

I assume this applies to any group home as well as nursing home?

RESPONSE:

Yes, that is correct. It would if it takes federal money.

QUESTION:

What if the state legislature fails to appropriate necessary funds to correct inadequate state institutions to comply with the court decisions?

RESPONSE:

Well, if you have a legislature that refuses to fund a state system which has been found as a matter of constitutional law to be out of compliance, the short answer is, you have what is frequently called a "constitutional crisis." You have literally a confrontation of at least two branches of government, and if the Executive Branch is on one side or the other, you have a confrontation of three. No, it has not happened yet. If you want to sort out the constitutional principles by which the conflict would be resolved, you would look to the supremacy clause which says that the U. S. Constitution and its principles are supreme over state legislation. That means that the Constitution which is, as we know, interpreted by the courts, must remain supreme in terms of its protection of individual liberty over action or non-action by the state legislature.

Ordinarily the courts want to avoid that kind of conflict and will go to great lengths to avoid it, and I think that's appropriate. The courts ordinarily would require the parties, the plaintiffs or the Justice Department on the one hand and the state on the other, to negotiate, to hunt for, a solution. Failing that, the courts cannot literally legislate appropriations in the

state so they would probably shut down the institutions, which they can do, and disperse the residents because the constitutional condition which is offended is a denial of liberty without due process. Now, that hasn't happened, and you can imagine the difficulties if it does happen. It would mean a release. It would mean difficulties for many of the residents. It would mean a great upheaval, but I think that we have, on occasion, come close to that. I thought that for a while, a year ago, that that might be the unfortunate result in Willowbrook, but the Government and the Legislature seemed to be coming through.

QUESTION:

Do you think there is a constitutional right to treatment, without regard to confinement, by the state or through some other state involvement?

RESPONSE:

Is there a right to treatment abstractly, that is, without regard to confinement by the state or some other state involvement? No, I don't believe there is, and I don't believe, at least with even the most generous interpretations of constitutional principles that one can make, can one create that right. You could imagine one but, quite frankly at this point, I don't think it is necessary for us to fight a battle of that kind because we are, in fact, able to deal with the most critical problems without reaching that point. Because the Constitution is the basis for any right to treatment that we call constitutional, one has to live within those principles that involve state action. I don't believe there is an abstract right to treatment, and I don't know of any court that has said so. I read all plaintiffs' briefs in the field, I don't know of any plaintiffs who have urged that position and prevailed.

QUESTION:

Would you comment briefly on the Donaldson case - the adverse ruling?

RESPONSE:

The effect of the Supreme Court ruling in Donaldson. That's a good question. We have not sat down and gone through a set of hypothetical games in the office as to what would happen if they rule that way, largely because that would take some time, and we're

hoping in the other direction, so we just haven't done it yet. We'd have time to do that after they rule, if they rule adversely. So I really haven't thought through the implications, but I would think that it would have several.

First of all, it would depend upon the basis upon which the court ruled adversely. If it chose to rule very narrowly, by contending that there was a defect in the case, for instance, or there was a factual condition existing, some element of consent, that they found existed in the Donaldson case that ordinarily does not exist, then to deny a relief in Donaldson to the plaintiff would not be terribly troubling. It wouldn't help us any, but it would not be a sweeping constitutional principle against the right to treatment. The court could grant relief to Donaldson on very narrow ground and while that would be better than denial of relief, it would not answer some of the broader questions now pending in our minds about the constitutional right to treatment. Now, if the court chose to deal with the issue broadly, then the stakes are much bigger in both directions. If the plaintiffs win, it will advance the field generally, even spilling over, if you will, in terms of constitutional principles to other kinds of civil commitments, whether for mental health patients, mentally retarded residents, juvenile delinquents, and the like. If they conversely chose to deny the principle on broad grounds, I would think that the chances for the continuing life in our program on the part of the United States Government would be very severely damaged. Then the question would be, "Has the court left room in its language for possible legislation under the 14th Amendment in ways that the Congress can deal with it?" Rather than give up at that point (our litigation would be adversely effective) I would propose to see if we could find a realm within the spirit of the decision to legislate, or try to.

Individual Assessment

Marie Moore

With this topic we will change from looking at the broad generalities around those things that are necessary to consider in protecting the rights of individuals who seem to need protective environments, to who is making the decision about what it is that people seem to need. I'm going to start out by reading a poem to you. It's called "A PRISONER FOR LIFE."*

My age is no secret - I will admit it;
I'll be forty this year in July.
All my life I've been sentenced to prison
But I swear I will never know why.

No jailer blocks the way to my freedom,
No bars at my windows can I see;
Yet I am bound like any common criminal
By Cerebral Palsy, more commonly called C.P.

It has robbed me of walking and talking.
Perfect hand use seems very far away.
It has left me with wheelchair and braces
And in them it seems I'm forced to stay.

*Used by permission of the author

Someone must be constantly around me,
 For I need people's care both day and night,
 To bathe me, feed me, shave and groom me
 And in general see that all I do is right.

For many years I lived at home with Mother.
 She's my best friend on earth. I love her so!
 I could have stayed with her forever,
 But before I must, I felt that I should go.

Now I live at our Foundation
 With sixty others like me, night and day.
 We get along and try to help each other
 In work, in school and in our play.

So come to see us, write or phone us -
 But, please, no pity on us... You see,
 Although our bodies are in prison,
 Thank God our souls are free!

This poem was written by Cameron Faircloth. The writer has given us an individual's assessment about his body, about his environment and his socialization. He has made a self-assessment of his needs.

processes
 of
 assessment

Today I wish to tie together those components of individual assessment that will assist persons with developmental disabilities, their families and those professionals providing services, so that planning on a continuum may be established. Within a residential facility, such as a state or private institution, four processes of individual assessment have been identified. Individual assessment processes should be used as tools to do four things: (1) establish an individualized plan that is based upon theory and principles of human development; (2) plan for appropriate intervention that will minimize the effects of the abnormal or atypical conditions, abilities and functions and maximize the development of skills; (3) plan for the situations or opportunities that will facilitate healthy growth and development; and (4) plan for the necessary resources that are needed for implementing the individual program plan.

areas of
 assessment

Assessments should include not only the person but also the person's environment. There are eight basic areas for assessing the status of a person. Each area of assessment should not only include what is considered within the realm of normality but also what is within the realm of abnormality, prevention and correction.

1. Orthopedic/Neurological. This determines his or her mobility, dexterity, communications skills, etc needs to have an indication of postural tones, reflex responses, automatic reactions, quality and quantity of the total body movements. The orthopedic and neurological status of the individual influences such things as mobility, sucking, chewing, swallowing, picking up pencils, blinking eyes, eye contact and so forth.
2. Medical Status. Such things as respiration, circulation, metabolism, congenital defects, all have an influence on how the individual can operate in his environment.
3. Dental Health. I am not only talking about teeth and gums and cavities, but oral sensations, oral defects, etc.
4. Nutritional Status. This is certainly related to metabolism, absorption of food, type of intake, excretion, etc.
5. Sensory Integrative Status. This involves looking at the visual, auditory, tactile, kinesthetic olfactory, etc. I'm not talking about acuity, but the whole integrated process.
6. Ability to Function. This area takes into consideration the skills that the individual has in communication, mobility, self-care and other activities of daily living such as finding his way to a different location.
7. Personal-Social Adaptations. Here we get into the area of safety, interpersonal relations and the big Pandora's box, sexuality.
8. Intellectual Status. I'm not talking just about I.Q., but the whole area of cognitive development and the learning style of the individual.

When we talk about the general medical status, let us use the example of respiration which is such a problem for people whom we find in extremely protected environments. Are respiration problems associated with the general care, or is it something that is a problem with the individual himself?

I must stress at this point that the above eight categories are only isolated for assessment categories but must be related to other

areas. I don't mean to suddenly divide the individual person into all kinds of systems, but in order for us to consider individual assessment we need to know what we are talking about when we talk about the whole person.. One cannot assess the status and behaviors of a person without doing an assessment of that person's environment because the person's behavior is related to the sum total of his or her experience.

personal
environment

There are nine areas of a person's environment that should be considered in the individual assessment: (1) eligibility for community services and resources, like the whole community support system; (2) the architectural and physical environment; (3) socialization opportunities; (4) family relationships (as we have heard in the past few presentations, many times people are in nursing homes just because of deteriorating family relationships); (5) relationships established in the residential care facilities; (6) social problems due to racism and classism; (7) utilization of adaptive equipment and assistive devices; (8) history of past experience within a variety of situations; and (9) the family support system, which should be considered separately from family relationships.

developmental
needs

In assessing base-line data for developing an individual program plan, there are multiple service needs that should be identified as part of the assessment. These service needs should include, but should not be limited to, the following: within the medical model - nursing, medical, dental, nutrition, speech pathology and audiology, physical and occupational therapy; within the educational model - education, social planning, vocational and psychological; and within models of community service - recreational and religious. In addition, there is the area of legal, protective and personal advocacy; an area that we just heard about from Mr. Pottinger. These services need to be assessed in relationship to developmental needs of the person.

analysis of
process

Thus far I've emphasized three basic areas of individual assessment: the person, the person's environment and the person's needs. The model of assessment should be based upon human growth and development principles. When we emphasize human development the assessors must have knowledge beyond the use of a check list which indicates only if the person can or cannot do something. We also have to analyze the process by which the person has or has not reached a certain developmental point. Since there are indefinite variables that influence the potential for development as well as impede the process of development, analysis of process is the key factor towards developing any goals and implementing any program plan designed to facilitate maturation or mastery of skills.

Assessment answers the questions regarding what the person can do, what the person cannot do and what the person has not been able to learn to do under specific circumstances. Analysis of process delves deeper into the component parts and evaluates those prerequisites that are necessary for task performance and for social behaviors. Analysis of process deals with the "why" and the "how" questions that need answers as well as the "what" questions of a general assessment. To view assessment and analysis through the eyes of an engineer, we say that if all systems -- the metabolic and neurological, etc. -- are not ready, or if the environment is not compatible, or if the expectations of others are not realistic, the appropriate task and the appropriate social behaviors expected within an individual program plan will not be developed.

I am reminded of a young man who lived at Central Wisconsin Colony, when I was working there. He lived in a room with 30 other residents. He was about 20 years old when he arrived at Central Colony from another institution. The first time I saw him, I was working with a group of aide mothers who were learning the principles and techniques of therapeutic care and handling. We were spending two hours in the ward area which was also the living unit of 30 residents. One of the aide mothers was assigned to this young man. When she found him, he was on the floor, curled up in a fetal position, staring into space. I see a lot of you shaking heads; you have met young men with similar behaviors. He had a soiled diaper, so one of the first things -- if we were going to discuss and implement therapeutic care techniques and feeding -- was that his diaper had to be changed. The aide mother and I moved him from the floor to his bed and had difficulty, the two of us, in changing the diaper because of the spasms and the scissored legs at the hips. After we'd done this, we decided what kind of position we could put him in to facilitate better feeding so he wouldn't aspirate, and perhaps he could start developing some sucking and chewing behaviors. This whole time, of course, the aide mother and I were talking. I had my arm around him, and suddenly I felt somebody stroking my arm. I looked down into these eyes that had been staring into space and behind them, or coming through them, was a great deal of intelligence, human feelings; all these things one gets in looking into the eyes of one's peers. The aide mother and I went "ahhh." Now for 20 years this fellow had had an assessment of zero level of performance. In fact, earlier he'd given us some resistance because we'd gotten him out of his fetal position, and suddenly he was stroking my arm and looking at me as if I were his mother or wife -- with this very intense

expectations

awareness

look. During the year thereafter I went into the ward one day to consult with someone and here was the same young man sitting in the bed because there was no chair that would really take his deformed body and make him comfortable; he was sitting there feeding himself! The problem solving of many specialists, in both the physical and behavioral sense, a lot of dedication of a number of ward parents, etc., changed his environment because people suddenly looked at him differently, and he started developing skills after 20 years of just lying there. I think this says something. A lot of times the assessment process becomes a self-fulfilling prophecy that unless the individual himself in some way can intervene, as this young man did when he stroked my arm and looked me in the eye with some intelligence, - I don't have an eye I.Q. test to be able to say how he went up on the scale, - but because of this, there was some type of therapeutic intervention, some type of social interaction. In other words, the assessment of progress has to have some type of involvement of the individual if we are going to move in our behavior.

Many times when we talk about "living arrangements" such an environment might be labeled "dying arrangements" when we see the incidence of:

- quick death from aspiration pneumonia, status epilepticus, kidney failure, chronic bowel obstructions, etc.;
- slow death from progressive regression of the physical status, malnutrition, circulatory disorders, etc.;
- living death from total withdrawal, self-abuse behaviors, increased deformities, social isolation, rumination, severe sensory integration distortions, etc.

the
best that's
in us

Can we develop living arrangements that offer the least restrictive alternatives and humane opportunities for persons in need of a protective environment?

I once heard a television speech given by Senator Hubert H. Humphrey in which he stated that "the times call for the best that's in us." He was speaking to the fellows of his political party but these words must apply to all of us who are charged with the responsibility to improve the quality of life for those persons who need special programs and protective environments. The best that's in us does not stop with sustaining life for another day.

Assessment must include the person's environment and available service support system if we are to provide opportunities for people to develop their highest level of potential in the physical, cognitive, emotional, social, cultural and spiritual spheres that make the total person.

I would like to read the definition and principles of individual assessment as stated in the Standards for Community Agencies serving persons with mental retardation and other developmental disabilities (AC/FMR, JCAH).

individual
assessment

Definition:

"Individual assessment is an empirical process that determines if, and to what degree, a person has developmental deficits, and what interventions and services are needed to enable the person to move toward increasingly independent functioning. The individual assessment identifies the present developmental level of the person, the conditions that impede his development and, where possible, the etiology of the disability."

definition

Principles:

"An individual assessment is necessary in order to develop an effective individual program plan. The interpretation of the complete battery of tests and examinations that are needed for comprehensive diagnosis and assessment requires interdisciplinary teamwork. Systematic appraisal of the pertinent facts that are determined by an initial interdisciplinary assessment and by periodic reassessments should be the basis for all services offered to a client. There should be a clear locus of responsibility for synthesizing, interpreting, and utilizing the results of the assessment components provided by different practitioners or agencies. The cultural and ethnic background of the client should be given full attention in the selection and interpretation of the tests and examinations used. The agency should be fully cognizant of the life style of the client and his family, and the time demands on the family during the assessment phase should be realistic," not only to the family but the individual himself. I added that last part -- it is not in the Standards.

principles

If nursing homes are to become community-based living arrangement alternatives for those persons requiring a protective or a full support environment with developmental care programs, the AC/FMR standards must be utilized as guidelines for developing adequate programs. I think at this time I would like to open things up for discussion.

AC/FMR
standards

QUESTION:

Do you see the importance of the client himself taking part in the assessment?

RESPONSE:

Definitely, because we want to think of this person as being capable of doing it, no matter how "retarded." Now, I know Pat is going to get into this in a few minutes, but the individual program plan must involve the person and his family. Certainly the assessment process should involve the individual. Many times we are not that sensitive to communicating with individuals, particularly if they have no speech or language that is similar to ours, and I think I said to someone at lunch, many times people who lived at Central Colony could communicate quite explicitly to me as to how they were assessing the program, as to whether or not they were crying or smiling, facial grimacing, etc. And one has to be very tuned in to this kind of thing so that there really is no level of performance that would keep a person from becoming involved in the assessment process.

QUESTION:

What about the role of the advocate in the assessment process?

RESPONSE:

There are many kinds of advocates that should be involved in the assessment process. We talk about the one-to-one advocate, the citizen or the parents or the best friend of a person who is going to have to help this person make some decisions and perhaps make some decision for him. So these people should be involved because there is no conflict of interest. There is minimal conflict of interest versus the professionals who

know what their budgets are, etc. If the person doesn't have an advocate legally assigned to him, then we'd better assess the system to see that such an assignment is made. There are some states that have protective service laws, such as Ohio, and these people definitely should be involved in the assessment process. Now I could go on and expand on that, but I think I'll stop right there, or else I'll be here the rest of the day.

QUESTION:

What kind of environment is best for doing an assessment? Is it best to do an assessment at a diagnostic center or the actual treatment center itself?

RESPONSE:

I don't think that assessment can be done only in one place, but that there has to be a plan for assessment so that you can see the individual in many kinds of situations. It should not be done in a little room with no windows and no doors as the only place, although it may be necessary if you're going to give an audiological exam. It should be done in places in the community because you are also assessing what services are available for them and so there has to be some mobility for assessment. Now, there is a restraint of time, and there is a restraint of money, so that by having an assessment plan, which should be an ongoing thing to test whether or not there is progress happening anyway. It should be spelled out in the plan how this is going to happen, and who is going to be involved and when. I would say that the biggest problem in a community assessment are the barriers, not only architectural but also attitudinal, but certainly the mobility barriers, so that you have to build this into the assessment. You couldn't find out certain kinds of information because the environment did not permit it or the body of knowledge did not permit it. That's never in the assessment; you see, the evaluator usually knows everything.

QUESTION:

Would you make some comments about the dynamics of the assessment process?

RESPONSE:

The speaker asked that we clarify the assessment process to say that it is more dynamic, that it is ongoing, that it is not in one place by

one person, etc. The reason I can't be more specific is that there is really no good model of assessment to draw on, and perhaps this is something that we really need to look at because this is a symposium, and there should be some very specific types of recommendations to come out of this body pertaining to that. I think that also when we talk about assessment as a tool for developing the individual program plan, we also have to include a process for monitoring within this assessment. Perhaps this is another role of an advocate as well as the role of responsible persons who are going to be a part of the implementation of the plan itself. Actually, Pat McNelly and I should be doing a duet up here because I think to isolate assessment from the implementation of the plan is to show a painting without a canvas behind it.

QUESTION:

Has NARC submitted a proposal to HEW to review assessment procedures?

RESPONSE:

I am unable to answer this question, but we will ask Susan Weiss if she is able to respond.

Susan Weiss: Under the Medicaid program the Early and Periodic Screening Diagnosis and Treatment program is mandated in every state. It's a program which is supposed to screen low-income children, who are eligible for Medicaid, for "physical defects," and I'm quoting from the law here, and "mental defects,"--also from the law. That term has been interpreted by HEW to include a very comprehensive screening process and where the screening turns up problems, the child must then be referred for diagnosis and treatment. HEW has never developed an assessment tool or a screening tool in the area of developmental assessment and screening. Recently they let a contract to the American Orthopsychiatric Association to develop such a tool, and the contract is not completed and the tool is not developed. NARC, along with the United Cerebral Palsy Associations, and several other organizations, has submitted comments to HEW regarding what kinds of procedures should be incorporated into a guide given to the states, but those recommendations deal more with the administrative structure, with things like outreach, how to find these children, than they do with specific screening tools, specific assessment procedures.

There is a mandate, and it's one which the states have never met, and the Government Accounting Office, which is the Congress's watchdog,

recently issued a report which indicated that very few states are implementing the Early and Periodic Screening Diagnosis and Treatment program to any substantial degree, and this is particularly true in the area of developmental assessment.

Marie Moore: Frequently when we talk about screening and assessments, we are just talking about screening and there should be a clearcut definition between the two. Gathering a certain amount of information to make people eligible for something is a screening process. An assessment process is an ongoing dynamic type of program that involves many people, including the individual himself and leads toward the development of the individual program plan.

QUESTION:

I was thinking about the process of assessment, why don't you talk about the transdisciplinary approach to assessment as perhaps a model of assessment?

RESPONSE:

The transdisciplinary approach is evolving, or has evolved, out of the Mini-Team Project and associated projects, in which they're looking at the specialists of several fields. In this particular case it was nursing, occupational and physical therapy -- to pool their bodies of knowledge in some way and to use their expertise in developing assessment tools so that many parameters of the individual and his environment could be examined. With this pooling of knowledge, the assessment leads toward program planning and intervention strategies which could be done by one of these specialists, with consultation from the other specialists. I think that this particular model does two things. It certainly improves the communication among various specialists so that everybody knows what they're talking about, and they're not just taking people into their own little rooms and using their own little jargon and finding out their own little bit of information and sending them on down the assembly line. It allows people to problem-solve in areas of the unknown. The process has almost become as systematic, when it is operational, as trying to get to the moon. There are so many unknown factors, and certainly working with the severely, multi-handicapped, neurologically damaged, profoundly retarded individual, there are so many unknowns. We've been working for thousands of years in ignorance.

The second thing a transdisciplinary approach does is that eventually it has an impact upon the cost factor because the more people who are involved in a transdisciplinary process the more the knowledge is pooled, and the more it is transmitted to the people who have the daily contacts with the individuals such as people we call the attendants or the nurses aides or the ward mothers or whatever you want to call them. The more these people become involved in the assessment process their skills will be enhanced to continuously monitor and intervene in a therapeutic or developmental fashion. So I would say that this is one excellent model for assessment, but again, the transdisciplinary model covers not only the assessment process but the intervention process.

QUESTION:

What is meant by empirical data?

RESPONSE:

I think empirical data, which is the term used by the Joint Commission and not me, implies that there should be some standard of measurement and that's why you need certain kinds of tools. Now, for the individual assessment it's only good if it's helpful in planning for that individual. I think the reason why a lot of us are forced into using it is because we're being made to say things about total groups of individuals and how much it will cost us, etc. But I also think that we need this kind of thing, and I'll use the simplest tool that I can think of -- joint range of motion. We need this kind of measurement on a regular basis to see if the intervention has promoted development, and also to know that it's not promoting regression or to determine whether the lack of intervention is promoting regression. If somebody had started collecting empirical data on joint range of motions on the first person who entered the institution, when the first institution was built, perhaps we wouldn't see the terrible, terrible uncorrectable deformities that we see today. So I don't think they're a bunch of nonsense. They're only a bunch of nonsense if we don't know how to use the information.

The Individual Program Plan

Patricia McNelly

My task is to discuss the individual program plan (IPP), which brings to mind the children's poem about the six blind men whose task it was to describe the elephant, as each of them touched a different part. As I describe the "individual program plan" it may be that each of us will come up with our own perspectives of what we think that this plan is all about and what we expect it to do for us. However, we have to consider it as part of a total system for planning care that depends upon input, process (the establishment of goals and interventions) and feedback, which provides evaluative capability. Assessment (part of input) provides data which influences the process of determining what the goals will be. The continuous evaluation of the plan is seen as feedback requiring assessment. The system can be seen as:

Input → Process → Feedback → Input → (etc.)

part of a
total system

There needs to be interdisciplinary involvement in identifying and reviewing the total needs of the individual, establishing the goals and methods, and setting up a system to provide feedback information. Is the plan working? If it isn't working, we'd better feed that information back into the system and re-evaluate. Have we established improper goals? Is our assessment incomplete or incorrect? Is our method inappropriate to accomplish the goal? This system supports continuous evaluation of what it is you are trying to accomplish and remains open to change because of it.

goals

How do we carry out the assessment portion of this approach? I recall a family with an 18-month old cerebral palsied child whom I met at a development evaluation center. Their evaluation began on Monday afternoon.

a
multidisciplinary
approach

On Wednesday I visited with them to see how things were going, touching back to see how the process of evaluation was being perceived. The parents said, "You know, it's funny. Everybody's asking us the same questions." The assessments were being carried out in a mechanical, ritualistic way using a multidisciplinary approach. Each professional took the child or the parents, together or separate, into a private office and conducted an assessment; then the next professional came along, etc. There were 16 different professional disciplines involved, so by Wednesday the parents were getting a little weary. You can imagine what was happening to their child, a severely spastic infant. How does he score in a performance test by Wednesday? What would he be able to do? Or even want to do? We found that the people in Learning Disabilities were telling the parents, "If you would feed him from this side and only give him food if he turns his head in this direction, you will get him to attend to the spoon." This came out during the staffing discussions, with the parents and all the staff present. At this point, the therapist exclaimed, "Good heavens, he can't do that! He's got an obligatory asymmetric tonic neck reflex. He can't turn his head voluntarily from one side to the other because of this reflex."

an open
system

This was a very bad scene and suggests that if we did "our things" together, using information from shared assessments, contributing into the system and working with that information in an open, cooperative, integrating kind of way, we'd have a much better plan. It would be a much more realistic plan in terms of how it fits the individual's needs. There is a real need to advocate for this open system, one that is continuously interacting with the environment. Such a system continuously gathers and receives information about the environment, the complex interrelations that are going on and the reactions to events that are occurring. This information is then used to signal directions and adaptations.

operational
goals

The IPP, as a system for delivering service, depends upon careful assessment. It depends upon careful review of past events in the individual's life as well as careful documentation of the present performance of that individual. This system uses operational goals that are observable and measurable. If there was ever a name of the game today, in 1975, it's "operational goals." Many find this a difficult area as we are not

accustomed to thinking along these very discreet, definitive lines. This is an area where we must learn and grow in our ability to define specifically what is to be accomplished through the IPP. We can learn to write good, comprehensive, useful kinds of goals, but I think that we may need some structured practice to facilitate our learning.

Feedback, of course, is all important to the system, and that brings us to documentation. If it isn't documented, it didn't happen. How else do you verify that something did take place? By documentation of outcome we report that something happened. The behavior changed. The performance changed. The conditions changed. We have (or have not) achieved the goal that was defined in measurable terms. Our system then has the ability to change; that is, feedback is used to change the plan.

documentation

The IPP must represent a very dynamic system. By that I mean no individual program plan should be cast in stone, never to be modified. It may need to be changed next week. The IPP has to be a responsive instrument, amenable to change because you should know, relatively soon, whether the plan is effective. If it's not working, then further assessment is needed to pinpoint the problem. You have to look at the method; how we are trying to accomplish this goal. You may also have to look at the goal; is that the appropriate goal? Are things out of kilter in terms of developmental sequence? Did we expect a behavior based on ability that isn't possible at this time? We do have to think about small increments in developmental ability rather than expecting giant steps up the scale. For example, if I'm totally dependent in eating, aren't there a number of tasks to learn along the way to independent eating? If we observe that the individual does not pursue the path of the spoon, or anticipate the spoon coming to his mouth, then we must start with goals relating to attending behaviors, visual pursuit and awareness that an event is occurring.

a dynamic
system

There are many different forms of feedback; the documentation of the day-to-day efforts of the resident-living staff, the periodic reassessment by the various professionals involved and the periodic review by all of the persons involved in the individual program plan.

periodic
review

Styles of interaction among people in different locations and places certainly differ. But the need for communication doesn't vary. Staff must get together periodically and regularly to discuss the progress of the resident because you cannot use a "cook book" approach in

developing and applying an individual program plan. Developmental behavior scales may be useful guides but they do not individualize in terms of the individual's response to learning approaches. There must be agreement on the kinds of approaches that are going to be used to accomplish the next step, to ensure continuity and consistency among all people involved in programming for that client.

goals of
assessment

Marie Moore has given us an excellent description of assessment, outlining the many parameters of comprehensive assessment. Some professionals may tend to concentrate on specific assessment tools, others may conceptualize and use a specific framework. For example, Maslow's "hierarchy of needs" comes to mind immediately when I begin to assess an individual. There is also a need to review the past, in terms of what's happened to the individual previously. We must have complete information in order to determine with the individual what the next steps will be. And we use continuing input to correct what we thought was an appropriate goal and to establish new goals in the future.

Goals define the outcome of the action plan. We must establish our goals before we even begin to think about methods. Once they are established, we apply existing knowledge of effective methods or develop innovative approaches. The goals guide us in communication because they give us a point of reference in terms of what the documentation shall be. However, it must be remembered that while the plan should be very comprehensive, it cannot encompass every aspect of the total individual. There also has to be freedom within the documentation to provide individual observations of direct-care staff, or of professionals working with that client. But the goals certainly assist us in gathering the information necessary to redirect program planning.

accountability

If part of the plan is not working, we may decide that we will modify the method, while the goal continues to be valid. Remember that we cannot be satisfied with a goal stated as "increase head control." What is the present ability in head control? That data should be available in our assessment information. Increase it to what? For how long? Under what kinds of conditions? Goals must be written very specifically; it's no longer appropriate to merely state "increase nutritional intake, increase head control, improve skin care." Could these goals be measured? Operational goal setting and documentation of accomplishment of goals is our means of accountability, not only to that client but to the community and the public we serve.

One basic framework to apply in developing the individual program plan is the developmental model. There is an expectation of potential, the individual will move ahead on the developmental spectrum. Change is expected, and we look ahead to the next level of development. We establish goals relating to that next level, and we seek ways of assisting individuals in accomplishing those goals. We expect and plan for change.

We don't accomplish change through random kinds of group activity, because it seldom suits each individual person. Applying developmental concepts, there is emphasis on what each person's specific developmental needs are, and planned approaches to enhance development. It is quite a different way of looking at people who are mentally retarded, in contrast to the disease or deviance orientation. It certainly isn't a "can't do" kind of orientation, is it? It is a "can do," because this individual has achieved his present level of development. We are looking ahead to the next step, but we are also looking at what he is presently able to accomplish. What does the diagnosis of microcephaly do to help in planning an individual's program plan? Is that useful? Would anyone be able to plan a program for someone using a diagnosis of microcephaly? Down's Syndrome? While a clinical diagnosis may be important for some aspects of health care within the IPP, the diagnosis alone does not convey the kind of knowledge necessary to facilitate the individual's developmental progress.

developmental
model

Now let me ask, Who is the developmental specialist on the interdisciplinary program team? Is there any one discipline that has the corner on that knowledge? I believe nurses know a great deal about growth and development. Others might say psychologists know about growth and development. Many would say that physicians know about growth and development. So we have a number of people who can contribute that information to the individual program plan and could all be involved equally. I like the phrase, "All of us is smarter than each of us." I think that's the way it ought to be in developmental programming; working together to pool developmental information. Integrating this information and applying the expanded knowledge base which comes through the participation of several disciplines, we can do a much better job of individual program planning.

interdisciplinary
planning

Basing program delivery on developmental needs and goals, we respond to changing needs because we plan for and expect change.

Anticipating change; we look for it; and we base new planning on the changes that occur as a result of our interventions.

anticipate
change

This area is perhaps the most critical aspect in residential programming, providing experiences that are goal-related rather than having things "just happen." If we are concerned about increasing the individual's ability to perform activities of daily living independently, we have to specify what those specific activities and behaviors ought to be. What is it we expect in terms of measurable, observable change in the individual's ability to perform in a specific activity? Then we must devise a method to support the development of that ability and create the environment to support that method.

Planned interventions must be consistently experienced. There must be accountability among those who deliver the program to provide sustained input to achieve the goal.

opportunities
to learn

In developmentally oriented programs, planned experiences are directed toward helping individuals increase their control of the environment. Consider the difference in one aspect of control between someone who must be fed each meal and the individual who has learned to eat independently. If someone is feeding you, they should consider how you like to eat your meal. Perhaps you like to eat dessert first because it tastes best when you are the most hungry. But suppose you are being fed by someone who thinks that's a terrible thing to do, and you get dessert only after everything else is eaten. Increasing control of the environment includes the opportunity to make choices and relates to even such small events as eating, as we strive to develop the competency of each individual.

It is not uncommon to find resistance to the concept of the individual program plan because these plans appear to be, and can be, a lot of work. It does take time to develop an adequate plan. Some people will say, "We spend all this time planning and writing it down; we just don't have any time to work with the residents any more. All you want me to do is come to these meetings and talk, and there are those residents out there, waiting for me to come out and work with them" If we are really going to individualize the service and provide developmental approaches, we must have a plan. The resident cannot be expected to provide daily direction on how care is to be given. Individual abilities and needs are expressed through the plan and direction is available to all who participate in that individual's program.

Have any of you been in the hospital lately? There are many disquieting things about being in a hospital, apart from being sick. The patient must relate to many personnel who change from day to day. People have days off, or they work different shifts. You just kind of get things settled, somebody knows you like certain things -- let's say you like Sanka instead of coffee. You have been able to get people oriented to that by sending them back to the kitchen for Sanka when coffee comes on your tray. However, this morning there is another unfamiliar staff person and you have to go through the same process again in expressing individual preference. The individual program plan, if available in writing and communicated to all who work with you, would save that energy and reduce frustration levels for all concerned. This is very significant for the clients we serve, who often cannot provide verbal direction for care-givers and need to use their energy in more constructive ways.

a plan
organizes
activities

The establishment of defined program groups, and the consistent assignment of staff to those groups, are essential components in the development and application of the individual program plan. Any residential service must consider that in its basic organizational plan. It must be done for consistency and continuity and to support the formation of the resident's personal attachments with significant caring persons. Service delivery individually tailored for each resident, not geared to the lowest common denominator or designed so as to be institution-supporting, will be greatly facilitated.

Even with stable groups and regularly assigned staff we cannot have consistency without a written program, providing continuing orientation to staff about what we are trying to accomplish with this individual. What are the goals that have been established? How have we decided to accomplish those goals? What can we tell those who are going to work with the client in the future about what we have been doing? Ongoing documentation will report what has happened in the past as well as provide information about the present plan. Let me give you an example. We have decided that it would be appropriate to work on the acquisition of two words during the next month with a certain individual. This could well be a shared goal among Speech, Education, Activities and Resident Living staff. Everyone who contacts the resident should be involved to facilitate the individual's expression of these words and a written plan provides the tool for sharing this information. The existing resources are mobilized in a more meaningful way. However, suppose that Education decided the words should be "red" and "green" and Activity Service decided on "ball" and "run," and another group

a plan
provides
consistency

decided on another two words. There goes the interdisciplinary approach. It is possible that the resident might increase his vocabulary, but it is also possible to diminish the effect of training. The resident becomes frustrated and less capable. We must establish priorities through the interdisciplinary approach. This may involve considerable discussion and even a few arguments about what is most important for the individual. During this process some people become very threatened.

cooperative
action

Differences should be resolved through interdisciplinary discussions and a consensus can be reached, or perhaps even a truce occasionally, so that the group will continue talking to each other when priorities become confused. Otherwise the resident is going to suffer. We must individualize the program and develop staff cooperation. Staff must work within the priorities cooperatively established and seek to improve them when necessary.

More objective treatment of the resident is also facilitated through the program plan. Subjective identification, in the more extreme sense, can interfere with effective programming. I think of the foster grandmother who continually slips ice cream cones to the resident on a 1,000 calorie diet. You know that's very warm and very loving, but it doesn't help the resident achieve a goal of a specific weight by a certain time. We can provide objective treatment of the resident through this system of organizing and setting priorities and establishing goals so that the individual's program isn't whimsical.

monitoring

The plan also serves as a reminder -- we know continuously what needs to be done because we have something in writing to refer to. Staff time is used developmentally, working toward goal achievement rather than engaging in random kinds of activities. We are measuring progress because we are looking for evidence of goal achievement. This factor is also helpful to people who have responsibility for supervising the work of others, looking at the whole process of program delivery. How do we know whether or not the efforts of staff are effective? Are we really helping the client? Is everyone contributing?

We can look at staff performance very objectively, in terms of the individual program plan. The supervision of direct-care staff is also much easier when there are specific kinds of activities, goal-directed activities, for them to follow. Because they participate in program planning there is also a greater likelihood that they will perform the activities described within the plan.

According to both federal and voluntary standards, representing quality services, individual program planning begins when the client enters the service system and is evaluated by an interdisciplinary team. For residential services, this is the pre-admission evaluation. The post-admission review and update is required within one month in both ICF and AC/FMR standards. The specific developmental needs must be identified and expressed in behavioral terms. The treatment, training and habilitation objectives are also established in behavioral terms. The program designed to achieve those objectives must be very specific and detailed; and within one year, review of the response to the program and new program planning must occur. For children, and others whose needs are changing rapidly, the review should be conducted more frequently. Each full review requires a new statement of objectives and a new statement of activities directed toward the achievement of the objectives. We're talking about a dynamic treatment and habilitation program, quite different from the custodial "until death us do part" program.

review

Why did the individual need this residential service? When those needs have been met and the desired outcomes have been accomplished, alternative living arrangements should be provided.

Within the overall individual program plan, there will also be sub-program plans. For example, Resident Living Services would develop a detailed plan relating to the activities of daily living, encompassing all segments of the 24-hour day when the resident isn't programmed in another specialized service, such as Education, Speech Therapy, etc. Each of these services would also have sub-program plans. All of these plans must be congruent with the overall plan. Plans within each service should identify the trainer, the objectives (detailed and behavioral) the schedule, the techniques or the method to be used, and the progress data to be collected. Review of these plans must be conducted at least monthly by a qualified professional staff member. That person monitors each of the program units within the total individual program plan.

The individual program plan should meet certain criteria. It must be specific to the individual. It must be realistic and comprehensive, relating to the total assessment of the person. It must reflect the ability of the facility and the resident to accomplish the plan - that it must be reasonable. That may raise the question - what is reasonable? The plan must be reasonable in terms of the energy of the individual, his ability to cope with the program and reasonable in terms of the resources to be used.

IPP criteria

the plan
must be:

- understandable
- current
- measurable

All goals and programs need to be developed using understandable terms, so that everyone can comprehend. There are certain complex terms which become a part of the normal vocabulary of experienced staff because of their level of sophistication. However, these terms may not be understandable to parents or new staff, and the plan needs to be understood by all. The plan must also be current - that is, reflecting current assessment, current conditions, current ability of the resident, current ability of the facility. Goals should be measurable, attainable with effort, sequentially okay, consistent with the assessments, realistic and reasonable. Goal setting should be done carefully and thoughtfully, because these are the defined behaviors that resources will be applied to accomplish.

The approach defines the method, individualizing how it is to be carried out with and for the client. The approach must assign responsibility for who will do it, when it will be done, where it will occur and the data to be collected. This structures the documentation necessary for evaluating what the method is accomplishing. Present federal standards require that there be a qualified mental retardation professional (QMRP) assigned to monitor the progress of each resident.

the QMRP

This person can come from a variety of professional disciplines but must also have special preparation in mental retardation or at least one year of experience in the field. The QMRP can be a nurse, a psychologist, a social worker, physician, a therapist or an educator. The QMRP must monitor the individual and his overall program plan to assure appropriate active treatment.

Who participates in interdisciplinary program planning? One example drawn from a residential facility included a physical therapist, who also served as chairperson for the group; the physician; the unit program coordinator; a nurse; three aides who consistently work with the resident; the activity therapy assistant; two teachers; the work activity therapist; and a secretary. Now that list could have varied, depending upon the needs of the individual resident. The interdisciplinary committee develops both short-term and long-term goals and assigns accountability for them. It is also most appropriate for parents or surrogates to participate in the development and review of the individual's program plan. If they cannot attend the plan should be communicated to them as soon as possible.

Within the residential setting there should also be a detailed resident living plan, describing daily living activities which are the responsibility

of the direct-care staff involved in that individual resident's program. The health care plan may be integrated within the resident-living plan, including goals and interventions to promote a positive health status.

How many goals should there be, either in the overall interdisciplinary plan or in the individual program units? We find that too many goals create problems and confusion. Priorities must be set so that pertinent goals are thoroughly communicated and receive specific attention. Monthly review of the total effort by the QMRP and periodic discussion of needs and necessary revision of the total plan by the interdisciplinary group should assure that quality services are provided. That is the responsibility we are charged with for each and every person we serve. As the President's Committee on Mental Retardation has said, "In spite of all the ideas and all the technology and atoms in the world, it all comes down to teaching one individual at a time."

one person
at a time

Environmental Issues

George Gray

I want to focus upon five principle points in this paper and recommend NARC action relative to the issues. I may be straining to cover all five under environmental issues, but they do represent concerns I have developed through association with mental retardation on one hand and nursing home operation on the other.

The five points concern:

1. The effect of the 1967 edition of the Life Safety Code upon spatial relationships and the consequent impact upon interpersonal relationships.
2. The need for programs for various use groups of skilled nursing homes and appropriate housing for those programs.
3. The generic skilled nursing home as opposed to the facility specializing in service to the mentally retarded as the appropriate way to go.
4. Subjective versus objective criteria for admission and retention in a SNF and what to do about it.

5. The private sector as a flexible instrument for SNF service delivery.

While nursing home companies or associations provide or list nearly every type of residential or domiciliary care under their sponsorship, my remarks are confined to skilled nursing homes as are defined in regulations for federal Title XIX funding. Some of the points I wish to stress, i.e. code applicability, are as significant for some of the other programs.

spatial
relationships

Historically, man constructed building with very simple spatial relationships. There were a number of rooms or spaces accessible one from another and various different functions, often multiple functions, were assigned to each space. Since access to one function might traverse the space of a very disparate function, there was always, even in the most elaborate of palaces, the possibility of accidental or deliberate conflict of interest.

A fairly recent example of this kind of building is the palace at Versailles. Groups of rooms were designated as the apartment of one person, or family, etc. These rooms, even to ordinarily private rooms, were not free from intrusion by outsiders because one never knew who was going through a bedroom, for example, to get to the next room. To assure privacy, there weren't light gauze curtains around the bed, there were real drapes.

personal
space

Versailles had very simple spatial relationships. One moved directly from a space of one function to another. But our health facilities of today have highly structured spatial relationships. We have a separate space for each function, and all of these separate spaces are linked by corridor systems. This is a completely different spatial organization. What happened then in the serendipitous or catastrophic relationships that developed in Versailles, depending on who happened to wander through and what their intent was, is quite different from that which happens now in the modern hospital. Now you find a feeling of territoriality in the patient room and some respect for the individual's personal space despite his vulnerability due to illness. Just outside the door is a hostile environment--the environment of the corridor system. There pass people who want to come in and stick needles in you, rubber-necking visitors and other passing by, all kinds of carts and corpses, etc.; a feeling of isolation and vulnerability results, as is pretty well known to all of us.

Some of our older health facilities used to have, and I presume a few still do, sleeping rooms for six or eight individuals--a kind of supportive social milieu developed in such spaces despite the relative intrusion upon personal space. The older occupants would be interested in knowing who the next customer would be and if he or she would be compatible with the group. They would develop opinions about how much better this room or ward was from the next one, and so on. The camaraderie that developed had a positive value because it allowed for a tolerable level of interpersonal action and reaction. Yet, today a hospital cannot be built like that nor can a nursing home. Customs, standards and economics of operation mandate in hospitals usually no more than two to a room with the overwhelming preference of individuals for a single room to protect their own privacy. Nursing homes are built up to four to a room in some instances, with the majority running two to a room. Still, the individual patient's preference would be for a single room. Now suppose we were looking for the situation that afforded the personal space and territoriality of the single room or perhaps two to a room at the most, and yet the small group interpersonal relationships that developed in the old hospital ward. We might find this in a "clustering" of spaces with simple spatial relationships, patient rooms opening to a shared or communal use space, then these clusterings or apartments linked to necessary services and other clusters through a corridor system. This would, in effect, combine some of the spatial relationships found in Versailles with the more highly organized corridor system taking advantage of each where appropriate. Such a design would afford the privacy, small group interaction, supportive of patient human needs and the organization for appropriate administration of services and for safety.

interpersonal
relationships

Our nursing homes are tied by law, by federal operational funding and by state regulation in most states to the Life Safety Code of the National Fire Protective Association. This particular code is of importance to us when we are dealing with human services because it is written from the objective of saving human life. Other codes had as their beginning the objectives of preserving a community or preserving the investment in the building, but this code is designed with a specific focus of concern for human life.

life safety
code

Now, you probably know, and if you didn't, I hope you will remember that the legislative authorization that enables the 2.5 billion dollars of expenditure in behalf of health care systems under Title XIX cites the requisite addition of this code as applicable in this country, the

the 1967 code

1967 edition. The '67 edition specifies the high structured spatial organization that I was referring to earlier. The 1970 and 1973 editions, however, read as follows:

"Paragraph 10-12-33. Every institutional sleeping room, unless it has a door opening to the ground, shall have an exit access door leading directly to a corridor which leads to an exit. One adjacent room, such as a sitting or ante-room, may intervene if all doors along the path of exit travel are equipped with non-lockable hardware, except as provided in 10-12-42, and this intervening room is not intended to serve more than eight institutional sleeping beds."

architectural
criticism

We find, then, in an updated edition of this code, an opportunity to cluster spaces in such a way as to lessen the isolation and dehumanization characteristics of our health institutions and to strengthen small group relationships with the benefits that flow therefrom.

Architectural criticism of residential institutions for the retarded has been, for a decade or more, reflecting a need for consideration of environmental factors such as this as important to support the developmental process in the retarded residents. Now we see need to apply the same logic in health care facilities providing services to others. Interestingly, although this position relative to codes is taken from the vantage-point of enhancing program objectives, the same conclusion, i.e., that the '73 code should supersede the '67 edition in law, has been voiced by Senator Frank E. Moss.* The view of the subcommittee, chaired by Senator Moss, was taken regarding hazards and abuses found in nursing homes.

code
revisions

The challenge before NARC, therefore, is to press Congress for deletion of the specific citation of the 1967 edition of the Code in the basic law and to permit regulations promulgated by the Department of Health, Education and Welfare to indicate the applicable codes and editions of codes, so that environments in SNFs can be supportive to all residents, including the retarded. Editions can be changed over time as experience causes the Secretary and the Department of HEW to deem it appropriate.

*Nursing Home Care in the United States: Failure in Public Policy. Prepared by the Subcommittee on Long Term Care of the Special Committee on Aging, United States Senate.

Point No. 2. From the newspaper reports I can only conclude that one of the universal findings in our country is that nursing homes lack adequate programs. The regulations and funding for nursing homes under Title XIX are biased toward meeting somatic care needs, and in the better nursing homes these needs will be quite well met, but nursing homes are being used for a wide variety of individuals with needs that extend well beyond those of somatic care. I'd like to read to you a brief quotation from a statistical note, No. 107, from HEW. This happens to refer to "Patterns of Use of Nursing Homes by the Aged Mentally Ill," but the point is applicable here. "The reduction in the numbers of elderly persons resident in or admitted to inpatient psychiatric services, particularly state mental hospitals, in recent years appear not to have shifted the locus of care of these persons to community based psychiatric facilities, community mental health centers and other outpatient psychiatric services to any great degree. Instead, they have been accompanied by substantial increases in the number of mentally ill and mentally disturbed residents in nursing and personal care homes." And, then farther on Frankfarther, * referring to these same data, postulated that the most probable interpretation is that we observe the emergence of a new pattern in custodial care for the elderly mentally ill. By this he meant that there appears to be disproportionate utilization of homes offering personal care only to those elderly being transferred from mental hospitals. This, along with documented evidence of the relative absence of psychiatric training for nursing home personnel, lends weight to the interpretation of emerging custodialism. And to the extent that this is true for the mentally ill, it would at least be, and I would suspect doubly so, for the mentally retarded. The point I am making is that the funding mechanisms for programs in nursing homes are specific only to the somatic needs of the population in residence. We are developing, however, a recognition of the differentiation within the SNF population with needs that go beyond that somatic care and should recognize the need for programming to meet those other than somatic care program needs. We either have inadequate or under-utilized funding streams to meet those program needs.

program
environments

patterns in
custodial
care

* Dwight Frankfarther, "Background and Position Paper on Mental Health Care for the Elderly", National Institute for Mental Health.

funding for
programs

I would suggest that NARC give emphasis to the identification of appropriate mechanisms for funding of the program needs for the mentally retarded in nursing homes and to convey information with regard to access to funding streams to nursing homes that will be accommodating the mentally retarded. This is much less a problem in the intermediate care facilities for the mentally retarded since the regulations already incorporate the program features which, as you already know, are increasing the costs there above cost levels in skilled nursing homes.

The consequence of lack of recognition of program need has been that no space has been provided in construction programs for skilled nursing homes for meeting such program needs. The program space one finds are those authorized under Title XIX. As a result, we find inadequate space allocations for the kinds of programs that will be needed by the mentally retarded.

community
need

Albert Kushlick* recently reported on his study of community needs, particularly on needs in skilled nursing care facilities, showing that in the population of the service area wherein he works in Southern England (which could be deemed to be a community) the numbers of individuals requiring skilled nursing care were so few in proportion to the like need of the total population and the resources available to meet the SNF needs so meager that by no stretch of the imagination could he assume a segregated service for the mentally retarded. It's easy to overlook the fact that the community needs may not be appropriately reflected if we're thinking in terms of specialized service. I would put to you the proposition that if we begin with any conceivable realistic definition of what the community is, that we will also draw the conclusion that the workload is inadequate to the segregation of the retarded in this type of service. Therefore, it is extremely important that we look at the funding, the regulations, the laws, the codes and the training of personnel in the skilled nursing care field and find ways of making those resources generically available to the mentally retarded.

The fourth point I would like to stress relates to service chasing the dollar. Others have spoken of the inappropriateness of placement of individuals in nursing homes, perhaps in some states more than others. I would submit to you that one of the principal reasons for this is that

* Albert Kushlick, M. B., B. Ch. The Rehabilitation or Habilitation of Severely or Profoundly Retarded People. Prevention and Health Maintenance Revisited, 1974 Annual Health Conference, The New York Academy of Medicine.

there are no objective federal criteria for admission or retention of individuals in skilled nursing homes funded under Title XIX.

criteria for
admission

What should we expect? We're struggling with the formulation and functioning of utilization review committees to evaluate subjective judgments relative to admission or continuation of service. This is a kind of backdoor way to cover the problem that could be addressed rather simply and directly if objective criteria were available to provide a basis for judgment.

HEW now requires written criteria or standards for judgment of the utilization review committee. This is a step in the right direction. Some states are developing objective criteria which are optionally usable by such committees.

utilization
review

I think the mentally retarded are particularly susceptible to inappropriate placement in nursing homes because a lower level of intellectual functioning is often associated with the kinds of physical needs that, in turn, are usually associated with nursing level care.

Criteria which may be considered usually cover the following categories:

1. Bedfastness
2. Incontinence
3. Various skilled nursing interventions
4. Various skilled therapy interventions
5. Functional status
6. Mental status
7. Other disabilities

Only two of these categories should, in and of themselves, constitute sufficient justification for the degree of health care in a SNF. The circumstance to be avoided is the association of "mental status" with "functional status" and possibly "incontinence" as a basis for placement of an individual who is mentally retarded.

What should NARC do in this situation? I would like to see NARC develop a position with regard to admission criteria for nursing homes including objective criteria to be applied for the mentally retarded. Hopefully, with selected objective criteria available to apply in the circumstance of admissions of mentally retarded persons to SNFs, many inappropriate placements will be avoided.

example

Now for my last point. I would like to refer briefly to my experience with development of both a skilled nursing home and an intermediate care facility. These happen to be for the elderly, but I think the examples are pertinent and the conclusions should be pertinent. In 1967, there were five of us who sat down together in Whitehall, New York, and decided that it would be appropriate to develop a continuum of care for the elderly. Our group expanded to 15, incorporated, and over the next six years, and after a great deal of struggle with bureaucratic red tape in New York State (it's quite different to be on the outside trying to work with the system), we were in business. We opened the nursing home in 1973. In fact, about three weeks ago we had our second anniversary party.

In the course of development, we had to demonstrate to the Health Department the marketability of the service and justify the need. A state agency does not have to do this if it decides either to rebuild an institution or to build a new institution, although it goes through a justification of sorts in order to secure appropriations from the executive and legislative branches of government.

justification

The unfortunate consequence of the relative freedom of a governmental agency to escape from marketability justification is that such services as are offered tend to preempt opportunities that may exist for preferred options and a higher standard of living for the individuals in residence.

We opened up, as I said, in 1973. Within six months we were in full operation. Example after example comes to me, not only within the state where I work, but in other states, that this efficiency in start-up is not the case for state-operated facilities. Whatever the reason, society gets vastly less efficient utilization of facilities constructed with public money and operated by public agencies. I submit this is another reason to look to the private sector in service delivery.

private
facilities

In the course of designing the building, we found that we were about three or four beds over the count we were supposed to have. Of course, in a state institution that would delight the bureaucracy because they're always looking for more space. In our case, we had to deliberately construct partitions to prohibit the placement of beds and to avoid exceeding the count of beds for which we had approval. The private service corporation cannot take liberties with service quantitatively.

After about a year of operation, the Health Department was extremely critical of the maintenance of medical records because the physicians simply did not complete their notes. Despite repeated warnings, this

condition persisted. We had 13 physicians providing service in both the skilled nursing home and the health related care facility and among the alternatives to solve this problem we elected the following. We notified all the physicians that they would not longer have staff rights in our facilities. We contracted with a group of four physicians to provide the service and very specifically outlined their obligations in a contract. Since then our medical records have been complete. The service to the patients has been good and evaluation by the Health Department now provides us with a clean record. Now, if we were a state facility, the physicians would be covered by civil service, and we couldn't have dismissed them if we wanted to. But even more important than that, we couldn't have influenced the choice of medical practice because of the special reserve privileges allocated to one special group of professionals. Here we were, a banker, an architect, a clergyman, a man who runs the ice company and others deciding that here in an area where we were getting inadequate service we had to cut and run, do something to improve service and make it appropriate "darn" soon, as we could ill afford the loss of the millions of dollars received through Title XIX reimbursement. So we did it. There's a great deal more flexibility in dealing with personnel problems in the private sector.

administrative
flexibility

Our Board decided very early that we would not refer people away from the facility because of abnormal behavior patterns. We elected to seek, instead, support of our mental health board (this relates to the particular structure for administration and mental health services in the State of New York, but it forms a pattern which would be applicable anywhere), basically for three things: 1) proper evaluation and placement of individuals; 2) training of personnel to deal with the behavioral problems that would occur; and 3) the funds for the additional program support needed to maintain people who did have mental problems in our facility. Based on those three points, we expected our staff to follow through. We found a supervisory staff member was not following the policy of the Board. She was slipping the people out the back door and into other placements when they didn't act "nice." So, we let her go. We hired somebody else and got services back on the track we wanted.

administrative
structure

We contract out our food service. A food service company runs our kitchen and provides the service. The inspector found that the hand-washing facilities were not kept clean. The kitchen was spotless, but the lavatory where the employees had to wash their hands wasn't kept sufficiently clean, and we got "D" marks for that. It was fairly

simple to call the company's attention to the contract they had with us and serve them our notice that "within 90 days correction would take place or they were out." That problem has been corrected as well. This kind of flexibility is very difficult to achieve within a state-operated facility. I'd ask you to refer back to what we were discussing yesterday with regard to the locus of establishment of standards, of licensure, of funding, of evaluation, and of service, and note that if there is an appropriate role for government in some of these, perhaps the NARC would be interested in advocating the role of the private sector within this constellation of services so that a check and balance within our system is adequately developed.

Family Involvement

Kathryn Gorham

Let me identify myself a bit. I am the parent of five daughters, one of whom is of special interest to this group because she is very severely retarded. Let me describe her further. Beckie sat at age two; she walked at age six. She is now almost 14. She has no speech; she is partially toilet trained. She is learning to feed herself, but is not yet at the point of loading the food onto the spoon, although she can carry it to her mouth and put the spoon in her mouth. She cannot dress herself nor assist in dressing. She cannot climb stairs, although, as I said, she can walk. In many respects she is a prototype of the retarded person who will require intensive care and supervision for the rest of her life. She is living at home now, attending an intensive training program with a staff ratio of one teacher or aide for every two children; so she is a very lucky girl, indeed.

She has had experience in residential placement. For the first nine years of her life I underwent a great deal of pressure to institutionalize Beckie - pressure from all quarters - friends, family, every physician that I encountered and from public and private school personnel. There was general agreement that the institution was the appropriate placement for a child like Beckie. I was made to feel guilty for not placing her. But I did visit the institutions that were recommended and found that they were the least equipped to help a child who obviously needed so very much help. When she was nine

pressure on
parents

crisis
situations

I developed a disc problem and could not lift her. Beckie's father had had a similar back problem for some years. So with both parents "disabled," we felt we had no choice but to find residential placement for her. She went off to a private residential school, and when she did so, everyone applauded and said, "That family has finally come to its senses." But my back got better, and I brought her home.

Then, when she was 11, the family underwent another crises, and Beckie went into residential placement in the state institution, a new regional center with 200 beds, not far from where we lived.

quality of
life

During the year that she was in the state institution I faced a dilemma. I had turned professional. I was working for the Montgomery County Association for Retarded Citizens as their community relations person, and I was out preaching the gospel about the importance of the community and neighborhoods for children, of homes for children and of families for children; and there was my own child living in an institution. It was a very real conflict for me. I had always, in fact, thought that family living was so important for children that I had troubled to adopt a Korean orphan. So it was very difficult for me to see a child, to whom I had given birth, in an institution. Also, I was an involved parent. I visited Beckie frequently. I became the volunteer ombudsman for the institution. I had the chance to take many, many second looks at a place which had, at first glance, looked very good to me. Sadly I learned that our model regional center for the retarded was not exempt from most of the kinds of "institutional-think" that we are all familiar with. It was uncomfortable to be so aware that the quality of Beckie's life there was so very much lower than that of my other children. Was that really fair? Simply because she was retarded? So she came home and began attending the intensive training program for severely, multiply handicapped children run by our ARC.

To conclude the account of my situation as a parent, at present I am working full-time. Three of my daughters are in college; one is still in high school. The job of mothering has become very much less demanding than it was in earlier years. Now I merely operate the control tower to the comings and goings of children who, though attending college, seem to be at home as often as on campus. (I think that may be the way colleges manage to stay afloat these days. They send their students home for months at a time!)

As a professional I have been dealing for the most part with families of children and adults who are quite severely retarded or who have multiple

problems and who are living at home. Many of them will be candidates for the institution or for nursing home care, if such care is available, when their families can no longer maintain them.

As I talk with these families, it is evident that they are in a state of stress, perhaps best described as "chronic" stress. Enormous energy, both physical and psychic, is expended on the daily routine required by their children. The parents tend to lack "survival skills." Most of the mothers complain that they are very tired. Their personal wellbeing has been pushed way down on the list of priorities because their child's wellbeing is more important. Most do not even have the survival skill of knowing when, how or whom to ask for help. And community, friends and family are not offering enough help.

parental
stress and
survival

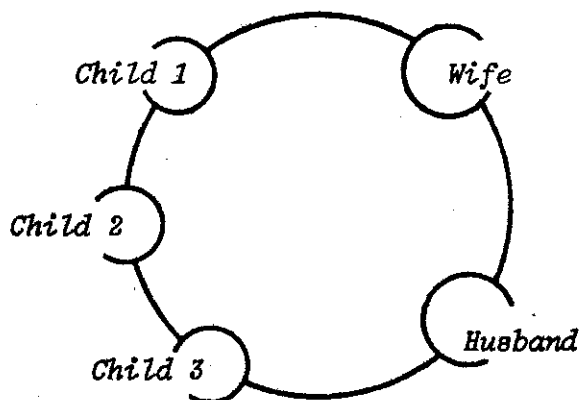
It soon became obvious that my main job as Director of Family and Community Services for MCARC should be to develop different support vehicles for families, ways of helping them learn the survival skills needed for daily life with a retarded person, ways of informing them about sources of help before the need for help reached the critical point, ways of analyzing their own resources so they could be mobilized. I started the year out with what I called a "ballpark orientation" for parents of young retarded children. As you know, parents are thrust into the business of having a retarded child without any preparation. It is a new ball game for them, and even the information about what resources are available is not always obtainable, and that can be a serious obstacle to getting help as it is needed. We dealt with parent-professional communication (in particular, parent-physician non-communication!), recreation, education, residential alternatives and, getting down to more personal concerns, to the family. We brought in a marriage and family counselor who "did his thing" with my group of 12 mothers. His "thing" was to urge them to talk out their angers, their frustrations, their anxieties and, indeed, they did. It evidently felt very good to them - so good that they wanted more - and when our six-session workshop terminated, the family counselor took over and continued for 10 more sessions. Now these are mothers whose children are in infant stimulation programs or in preschools where a lot of support, a lot of positive thinking is available to them. One of the mothers said to me, very frankly, one day, "We're all so tired of all you supportive people telling us how great it is to keep retarded children at home. What we really need is somebody who will let us talk about our resentment, about what a really lousy deal mental retardation is for us and our kids!"

learning to
cope

making
pressures
tolerable

Another of our workshops involved a consultant who I thought might be helpful in teaching mothers how to analyze and mobilize their own personal resources. He came to us knowing little or nothing about retardation; most of his work was with business firms, physicians, city managers, people whose professional lives bring them under too much pressure and whose "person-ness" is in danger of being lost under the enormous demands of their work. I had heard Charles Seashore, a social psychologist, speak on the radio, and it seemed to me that what he talked about - the reordering of one's daily agenda so that pressures are tolerable - was an extremely important message for mothers of retarded children too.

When he arrived to talk with our mothers he apologized for knowing so little about retarded children or their parents, but went on to tell us the kinds of things he did with his usual clientel, under the sound assumption that stress is a human problem -- not unique to families with retarded children. He suggested a tool for helping individuals analyze their own "support systems." He drew a diagram that looked something like this:



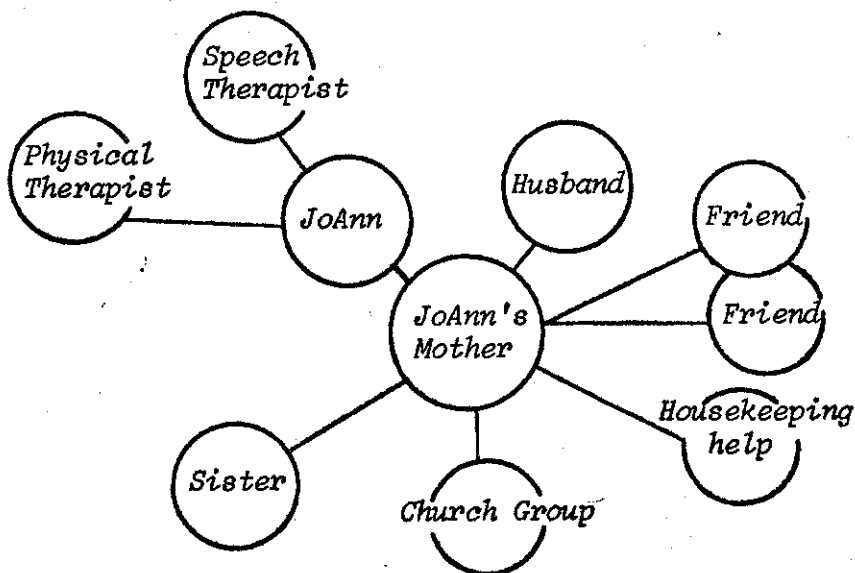
Now, in low stress situations, family members are usually sufficient support for each other. Each can go to another for emotional support as well as practical support. But in high stress situations, Dr. Seashore suggested, the members of one's family may be the least able to offer

support to one another. Each should have his own "support system" outside the family -- people to go to for emotional or practical support in times of high stress -- not necessarily professional helpers, more likely friends, neighbors, acquaintances, people who can offer different kinds and levels of help for different needs.

parent to parent
support
systems

It was somehow a new and rather threatening notion. Most of us are used to relying on our nuclear family for low, middle and high stress situations, and the thought of changing such patterns of behavior takes getting used to. But his observation certainly seemed valid for many of the families I have spoken with. They lean hard on each other under a circumstance which I have described as one of "chronic" stress, of high vulnerability to crisis, having a severely handicapped child at home. Battle fatigue may be inevitable for any family if "fresh troops" are not brought in on occasion.

Last night Gene Patterson introduced us to JoAnn, a young adult with multiple handicaps, living at home. If we sat down with JoAnn's mother and asked her to draw her "support system" it might look something like this:



Here's JoAnn's mother; her handicapped daughter; here may be a sibling. Here's her husband. JoAnn, as I remember, had a physical therapist as part of her support system. Who else did she have? A speech therapist. Her mother, no doubt, has a couple of friends. She is very likely leaning hard on her husband. She may have some kind of housekeeping help. Probably her extended family is geographically removed, but she might occasionally pick up the phone and call them when she needs them. She may have a garden club (or a bridge club, or a church group, or a book club). But I suspect that would complete her support system.

isolation

Now I know Gene said that JoAnn was suffering from personal and social isolation in a very real way, and we should be deeply concerned about correcting that isolation. But we should be equally concerned about her mother's social and personal isolation. I am sure you have all heard these statements from parents: "I need more friends." "I haven't been to a movie for a year." "My husband and I find it easier to stay at home than go out."

option
deprivation

We also heard Gene describe the option-deprivation from which JoAnn suffers. Having no alternative to her current way of life, she has no opportunities to make choices, to become involved in decision-making, no chance to feel the freedoms of having choices, of making her own decisions. I suspect that JoAnn's mother, too, is deprived of such freedoms. She, too, does not have options; she, too, is involved in too few decisions. They are made for her simply because of the exigencies of caring for JoAnn. It is one of the realities that parents learn to live with. But certainly the community must offer more home support than it does if normalization is to be taken seriously.

respite
services

Now when somebody draws his own support system, Dr. Seashore usually asks them to put in one corner the agencies or people from whom they want or need more support. What some parents put down in the "unsupportive" corner of their chart is our state institution. They wish it were a viable part of their support system, but it is not. It is increasingly less able to offer viable respite care. Originally beds were reserved for families needing respite care, either on demand or on a regular basis, every weekend, or every other weekend, for vacations, in times of crisis, etc. Those reserved beds are no longer available. State-level, budget-motivated pressures came to bear on the institution to fill them with full-time residential children. Consequently, no beds are available for relief care unless parents of children in residential care take their children home for weekends or for longer periods of time. Well, most parents are not taking their children home for weekends, often for valid

reasons, and there are precious few beds emptied for community use. For the individual family in the community who needs relief care, the right bed in the appropriate unit must be free at the right time. That match does not often occur.

I do not think Maryland is unique. Like everyone else, we are talking hard and fast about deinstitutionalization. We are urging families to keep their children at home, and yet there is a chronic shortage of relief care of any sort, certainly too little to permit families to lead "normalized" lives. They are not living in the least restrictive environment possible. They need a great deal more home-management support in order to approximate the lives their friends are leading.

So much for the plight of families who are still managing to keep their seriously handicapped children out of institutions, nursing homes or other residential facilities. I would like to talk about what goes on between the family and the residential care facility once the decision has been made to place the child (or adult). Parents often come to the residential facility with an accumulation of emotional baggage that can make any dialogue between parents and staff very, very difficult to achieve. Let me suggest some reasons why.

parent's
role

Yesterday, Dr. Clements outlined the reasons for placement in institutions or nursing homes which are currently acceptable to enlightened thinkers in the field. Certainly the first reason he gave, compelling medical needs, and the second reason, compelling training needs, are two that parents would feel comfortable about. The third, the inadequate home situation, the non-coping family, implies family stress and its concomitant, distress. Inability to cope, for whatever reasons, does not bring with it freedom from ambivalent feelings about residential placement. The parent is bound to feel anxious; he is bound to feel regret; he is bound to feel guilty about sending his child "away." And those feelings will influence his behavior after the child is placed. Typically this is what happens. It gets harder and harder for him to visit his child. The visits are painful; each one is a reminder of the trauma of separation. The child is left again; the parent relives his pain again. So parents tend to visit less and less frequently.

separation
and conflict

Also, when one spends time at institutions or nursing homes, one is very likely to see their inadequacies; and most residential facilities are inadequate. That is painful too, admitting that the environment in which one has asked one's child to live is not what it should be.

understanding
the parent's
perspective

As for confronting the inadequacies, complaining about them and demanding that someone do something about them, few parents will. Most will be afraid to rock boats for fear that their child could be sent home again, with his bed promptly filled by someone else's son or daughter. In other words, it is probable that communication between parents and the institution will be difficult and may cease completely -- unless a special effort is made to help parents and institution understand each other's perspective. The staff must understand why the parent has placed his child, how he is probably feeling about it, how those feelings are likely to affect his behavior, why the parent may be angry, why he may knit-pick and criticize, why he may not want to visit. And the parent has to be helped to understand why things are as they are in the residential facility, why life there will be different for his child. If he understands the "why's", he may find the differences less anxiety-producing. He may even be able to help the facility improve. So time must be taken at the point of admission and during weeks following admission to establish an understanding on the part of the staff of the parents' perspective and an understanding on the part of the parent of the institution's problems.

parent
involvement

Now, everyone here knows that family involvement after residential placement is a good thing. Parents say it's a good thing; staff members say it's a good thing; it even says so in the nursing home surveyors' training manual. Look on page 44: "...Perhaps this single aspect of the whole philosophical shift is the most important. The family is becoming a much more integral part of the active treatment process and the family is included as a living and vital force in the resident's life. If indeed the goal of upgrading services to the developmentally disabled is to be realized, then the family should always play a direct role in whatever services are provided." So everybody's for the family, but curiously, as one goes through the rest of the surveyors' manual, the family does not appear again. And the reality of family involvement with children in residential placement anywhere is that only 10 to 20% of the parents stay involved. The fact is, they are really not encouraged to do so.

I have implied that understanding the family and "where they are" should be a part of the inservice training for the staff of any residential facility. A second opportunity comes in staffings, whether they be interdisciplinary or multi-disciplinary. The parents should be there. Typically, however, the physician, psychologist, speech therapist, physical therapist, teacher, etc., come together to staff the child. Rarely are the aides from the unit, the staff members who know the children best, invited to participate. And why not the parents? I have

never understood why I had to sit outside the door while professionals talked about my child and her programs. Even such a decision as whether or not a child is ready to return to his home is discussed without the parent present! Parents should habitually be invited to participate, urged to attend and be made a respected member of the team.

Also, most residential facilities, private or public, do not take into account the impact of separation on the children and the risk of emotional damage if the child is made to feel abandoned. Often parents are not allowed to visit for the first month to six weeks. How could a retarded child not feel abandoned under such circumstances? I suggest that the admission process include rehearsal for separation as essential for severely handicapped children who cannot understand explanations. There should be a visit. There should be an overnight, and then there should be a stay of a few days. Severely retarded children should be run through the process. And going through such a rehearsal will have an effect on the families too. It will be their first experience in "program involvement." The goal of this program is adjustment. The program is separation-rehearsal. Objectives can be defined, criteria set down, observable behaviors noted and progress charted! I am not being facetious. Any child's "program" should include all steps of such interaction with his family. Interaction must be taken that seriously.

separation
and
adjustment

To reiterate, please keep in mind the idea of normalization for families who are keeping their children at home. It is terribly important. Parents need more support. But, given the advisability of residential placement for certain children and given the good of parent involvement after placement, I would hope that the trend towards small residential facilities continues; among other advantages, communication between the staff and the family can occur more naturally and more easily in a small facility. The smaller the place, the more easily accountable the people in it are for what goes on there and the easier it is for the parent to know who he should talk with when problems arise. Parent involvement of a more formal sort is vital too - as part of staff in-service training, as part of adjustment of the child on admission, as part of his program and as part of all staffings.

members of
the team

Thank you for listening.

Community Interaction

Allan Bergman

Many, many centuries ago wise men were to build a near perfect city. The only roads leading to the future city were small and impenetrable, and the terrain beyond them was unknown. No man, not even the wisest of them all, believed that the roads could be traveled, nor that the terrain beyond could contain and support the monuments that mankind deemed desirable in a city. Thus, Utopia remained unbuilt and the pathways did not become well-traveled roads.

Centuries later, a more intrepid breed of wise men was given the same task. Again, they saw the roads as near impenetrable, although they felt the terrain beyond them to be perfect for a new city. Tools were forged and solutions created. A few wise men were successful. Each created a city to resemble his own home. It was an arduous task and each architect toiled in isolation and despair.

Now that it seemed assured that cities could be built through difficult roads of access, bitter fights ensued about the roads into the city.

The terrain of the future city is the retarded citizen's destiny. The roads of access and egress are his or her reciprocal interactions with the environment, and the impenetrable road represents community fears, prejudices, rejection and resistance to change. And the wise men are you and I, and perhaps, if we are wise, we'll include retarded citizens as wise men too.

a common
interest or
interdependency

My task today is to discuss a community's interaction with a nursing home (or other residential facility) as it relates to persons whom we have labeled "retarded." According to the standards promulgated by the Accreditation Council for Facilities for the Mentally Retarded, a community is defined as "a general population having a common interest or interdependency in the delivery of services." In reality then, a community is nothing more than people, their structures and their interactions.

Based upon yesterday's and today's presentations, I am not sure we know exactly what constitutes a nursing home, but I trust we would tend to agree with Dr. Clements' criteria which imply that a nursing home would be serving only a very small, finite number of retarded persons.

What do people-the community-know about nursing homes? A survey of nursing homes recently has been published by the Department of HEW. I believe that a part of this survey was summarized in the March 31, 1975, issue of U. S. News and World Report under the headline, "The Spreading Scandal in Nursing Homes." Within this critical article the following profile of an individual residing in a nursing home was portrayed: An average age of 82 (95% over age 65); white; female; four chronic or crippling disabilities such as cardiovascular disease, fractures, senility or arthritis and more than half are "mentally impaired;" average stay of two years or more.

images

During the past several months, the following headlines have appeared in my hometown newspapers: "Third Area Nursing Home Loses Contracts With State;" "68 of 105 Hospitals Flunk Medicare Check;" "Skilled Care Facilities Fail Fire Test;" "Orderly, Home Sued in Assault;" "11-Point Program Drafted to End Nursing Home Ills;" "Nursing Home Residents Complain About Abuses." I submit to you that headlines such as these are appearing in news media throughout the land and that they create the images which the community-John or Jane Doe-hold as "nursing homes."

terminology
and trends

What do John or Jane Doe know about mental retardation? I am not sure: But I hope that you and I - and all persons intimately involved in the field of mental retardation - are caught up in a time of tremendous and rapid change; a time of important new terminology and trends; the Principle of Normalization, the Developmental Model, individual program plans, least restrictive alternatives, accountability, consumerism, ICF, AC/FMR, to mention but a few. You name it - we've got letters for it. If we don't we'll make some or create new jargon. But these terms, which reflect the main changes in mental retardation service systems, are not known by the community.

Let us look back for a moment to review our history and determine the vestiges of our past which still remain with John or Jane Doe. Wolf Wolfensberger, for those of you who may not be familiar with his work, has performed a systematic analysis of the historical attitudes and trends which have determined our approaches to service delivery systems for people who are retarded. Without belaboring the point, the major documented trends are that of the retarded person as a sub-human organism; as an object of pity; as an object of charity; as an object of ridicule; as an unspeakable object of dread; as a holy innocent; as an eternal child; as a sick person (the medical models); as a menace to society (criminals, troublemakers). I would suggest, unfortunately, that many of these models - these images - these perceptions, are still with us in the communities in which we live today - far more than we would like to admit. They have generated the stereotypes, fears, myths and prejudices which pose one of our major obstacles in effectively promoting community service systems and community interaction. All of those models have one thing in common; they are very dehumanizing. The essence of dehumanization is to respond, to a significant degree, to a human being as if he were not what he is or could never be what he might be. As a result of this negative history, change began to occur.

attitudes

In the mid-sixties a principle of human dignity developed, particularly in Minnesota, in all types of "institutions;" correctional facilities, mental health facilities, mental retardation facilities. From that we then bridged to the Developmental Model of Retardation - a dramatic shift from the custodial, dehumanizing models. The Developmental Model presents the human organism who happens to be retarded as a developing human being. This model is based on the assumption that 1) life is a process of change; 2) development is sequential, orderly and predictable; and 3) the rate of development can be influenced. It really is sad to look back at our history and think of the hundreds of years that had to go by before we could make these rather simple statements in terms of what we know about "normal" human growth and development, but which we didn't think were applicable to people perceived as deviant.

the developmental
model

In 1969, the Principle of Normalization (in my experience a mixed blessing because of the word, not because of the concept) appeared, and we allegedly began to "normalize" people. The term became misinterpreted to parents and to our communities who believed we were saying that no longer are people who are retarded, or have other developmental problems, handicapped. "They are normal." That

normalization

isn't what we wanted to say, but that's how the message was communicated. Perhaps we ought to use the words "humanization" or "individualization" when we talk about the principle or concept of "normalization." The formal definition has been used many times here, so I'll not review it except to say that normalization does not mean "normal!" It does not mean good or bad! It does not mean moral or immoral! It does not mean being or doing like everybody else! It does not mean being deprived of all choices! Unfortunately, many of us have tended to categorize normalization in such dichotomies. Normalization focuses on the individual human being and that person's uniqueness as a living organism with assets and liabilities, needs, drives, desires and flesh and blood, just like you and me.

expectations

Within a few short years, we were caught up in turmoil - changing models, changing systems - trying to undo hundreds of years of negativism and self-fulfilling prophecies. That is, we got what we expected. If you expect nothing, you will get nothing; if you expect very little, in most cases you will probably get very little. And those were the dictates and the mandates of our programs. Those were the messages we gave to our communities and to our facilities; in many cases from professionals and to professionals. We had labels, groupings, categories and pigeon-holing. We failed to recognize the "person" behind the label.

the person
behind the
label

The prevalence of labeling stereotypes recently was researched with future educators. Yesterday we picked on doctors and nurses. Today we will pick on educators. The researchers (Salvia, Clark and Ysseldyke, 1973) attempted to determine if stereotypes of exceptionality are maintained in the face of normal behavior. In other words, when teachers encounter intellectually normal children who are improperly labeled, will they retain the stereotype by rating the behavior of children labeled "gifted" more positively than when the same child is labeled "normal" and by rating the behavior of a child labeled "retarded" more negatively than when the same child is labeled "normal?"

In this experiment, two groups of undergraduate students in special education (N=48) and general education (N=117) were randomly assigned to three experimental conditions. Using a checklist consisting of 27 items arranged in five categories (attitudes and reactions toward adults, attitudes toward tasks, attitudes toward own performance, motor reactions and verbalization), the subjects were asked to rate a mentally retarded, normal and gifted child. Each subject completed three separate ratings. During the first rating, the subjects in group one observed a child on videotape who was designated as mentally retarded. The

subjects in group two observed the same child performing the same task but were told that the child was gifted. The third group observed the same videotape but were told that he was normal. After viewing each tape, the subjects were asked to rate the child. The three children rated were Caucasian boys (ages 6, 8 and 10 years) who had been previously determined to possess normal intelligence and to be free from obvious sensory or physical impairment. The findings of this study indicated that the children who were labeled "gifted" were seen more positively than children labeled "normal" on attitudes toward the task and toward own performance. Children labeled "retarded", however, were rated less favorably than children designated "normal," on all five dimensions of the checklist. It would seem that even teachers who have been trained to react mainly to observed student behavior still have a tendency to retain stereotypes of "handicapping conditions" even when the handicapping conditions are not present.

stereotypes

We are all culpable, or potentially culpable, to stereotyping and to using convenient labels; physicians, nurses, educators, psychologists, social workers, lay people. We're all guilty. The impact of societal stereotypes on individuals perceived as "deviant" recently was portrayed on an episode of the Archie Bunker program. An individual who had been released from prison on a pre-release work training program was performing some plumbing repairs for Archie. After constant harassment by Archie, the man stated, "I'm going back on the inside until they rehabilitate you folks on the outside."

Retarded citizens in my community of Dallas received similar treatment early last year. Our county MH/MR center had deposited earnest money to purchase a duplex in a blue-collar neighborhood. The duplex was to serve as a hostel for retarded men returning to the community from a state school. The home met all of the ideal criteria including accessibility to recreation, transportation, shopping, etc. The blatant prejudices of the neighbors surfaced rapidly in the form of too-often heard cliches against other minority groups. A woman who led the neighborhood opposition made a statement which I will never forget. "We're not against the program itself. We feel it is good. But we bought our homes with the purpose of raising our families in a healthy, wholesome residential atmosphere, and we just don't think we can do it with this project there.... There are plenty of young children passing through that alley behind the house. Especially in the summertime, lots of young girls pass by in swimming suits."

perceptions
of deviance

It is these psycho-social barriers which significantly enhance the difficulty in establishing truly "community-based" residences and supportive services. The community must be the focal point not only of the community-based homes, but also of the continuum of services. Homes without services offer nothing to enhance positive human growth. Homes with no community interaction are not normalizing and inhibit growth.

readiness
for failure

It is my contention that an individual's behavior is a function of the constant process of interaction between the individual and his environment. Services provided without a concern for the social aspects of an individual's life are not fruitful. If the environment is a poor one or the individuals within it are unwilling to understand the retarded person, then the resident's readiness for failure is increased and the positive aspects of his or her behavior are not going to be reinforced.

As Gene Patterson pointed out yesterday, learning still occurs under these conditions, but it is negative learning; no hope, irrelevant and distrustful. Therefore, all community residential programs must look outward to the larger community. The staff must seek to foster relations and strengthen the ties of the home's residents to the social life of the community. This interaction is strongly promoted within the ICF/MR and skilled nursing facilities regulations and the AC/FMR Standards; the latter of which must, in my view, be the foundation upon which to design and develop all community service systems.

access to
opportunities

Our mental health colleagues point out that coping competently with life's stressful situations develops self-confidence. Much of our zest for life, they contend, is stimulated by the need to cope, to take responsibility, to seize opportunity and to meet challenges. At appropriate levels we cannot deny these experiences to our retarded citizens in nursing homes or other community residences.

sensitivity
in
language

Another related community issue is our language. Our words reflect our values or our thinking. If we talk of retardates, mongoloids, slow, etc., we see the disability as paramount. As Burt Blatt suggests, "He who controls language, controls everything. Words are the big sticks of the modern age." We have a multitude of words at our disposal, but we need to understand our vocabulary and its role in the problem. If we categorize people by labels, we must unlearn the labels and re-learn, and then teach others that all people share similar abilities and traits and also that we are all different. We must be the leaders in developing this sensitivity to people in our communities in our own language.

Bernie Posner, Executive Director of the President's Committee on Employment of the Handicapped, has also addressed this issue. "We can be careful of the words we use. Why can't we stop calling retarded people 'retardates' or 'EMRs' or 'TMRs' or 'clients' or 'children,' regardless of age. Why can't we call them 'people who are retarded' ... not only communicating with the outside world but when we communicate with one another." I think some of our own prejudices too frequently slip into our in-house discourse.

Yet we catch ourselves coming and going; on the one hand, stressing individuals and normalization; on the other hand, for the sake of funding, caught in labeling traps, diagnostic categories: Crippled; developmentally disabled; potential recipients of this; substantial handicap to employment for that; non-feasible for this, maybe for that. Think how confusing these messages, which exist in our everyday service systems vocabulary, must be to the general public - the community, if you will - as well as to the person who is retarded or otherwise disabled.

labeling
traps

We talk of "beds" - that's a very dehumanizing term. Why not talk of personal living arrangements, if that's truly what we intend. Have you ever considered the names of some of our facilities? What images do they convey? Angels Incorporated; Loving Care Opportunity Center; Helping Hands School; Sheltering Arms; nursing homes; a medical model - a person who is sick, debilitated. Susan Weiss pointed this out in terms of some of the regulations in the agency which is monitoring the skilled nursing care in ICF facilities. I think that is a potential trap also.

service
identification

What about the location of the residence? I think Wolfensberger refers to the concept of "juxtaposition." Do we locate nursing homes adjacent to hospitals or funeral homes, or on dead-end streets, or at the edge of town? If so, what subtle non-verbal message are we transmitting to the community?

location

Our community residential facilities, if we accept the fact they are people's homes, must be located within real residential neighborhoods and should be accessible to the same services you and I would like to have in our neighborhoods; shopping, recreations, religious facilities, education, vocation, medical, transportation, etc. And how about our vehicles - the signs and labels that we rationalize putting on them because of free advertising and maybe we'll receive an extra dollar or

two in the mail? But what is it really saying? There go the deviants - there go the weirdoes down across town. How about the clothing and the hair style of the people we serve? Are they dead giveaways, or do we say it doesn't matter? They don't know the difference. If we do, then that's what the community will also believe.

So, in simplistic terms, a house is not a home, and a home is of limited developmental benefit without a positive community.

How then do we change the community? Well, it's not easy; there are no simple rules because each community is different; and what may work in Omaha may not work in Detroit, and what works in Detroit may not work in Dallas or Los Angeles. But remember, a community is people.

public
perceptions

Public attitudes resist change. They can withstand some extraordinary pressure for change on certain highly tense, emotional issues. The process of change produces anxiety because we are all creatures of habit. To introspect and to modify our behavior requires an expenditure of psychic energy. Many individuals in the community will accept our concepts intellectually but not at a personal level. Karl Grunwald, the Director of Mental Retardation for Sweden, says we must go through a process - and this will be a new one for some of you - a process of "deintellectualization." That's almost as tough to say as "deinstitutionalization." We have to deal with people's fears, their ignorance, their stereotypes and their myths. In their perceptions they are very real, and for us to deny their existence is a sham. We must deal with facts.

legislators

I think Congressman Claire Burgener gives us an interesting example of dealing with a relevant issue; education. "I remember an interesting debate I had with a fellow senator of mine in California. We were debating special education classes, and he said, 'You spend all this money on these kids, and you work with them two years and all they learn is how to go to the toilet.' He's a good man; he is not evil; he just did not know. I said, 'Senator, if I had to choose to learn one of two skills in my life and one was reading and one was toilet training, I would take toilet training any time.' That is very, very important learning, and I don't think that we think about it often enough." And now for some learning - I hope - for you.

action
steps

I have prepared 15 action steps that I would like to share with you as possible ways to better interact skilled nursing homes and ICF/MR facilities' programs and residents with the community.

1. I would not advocate town hall meetings nor door-to-door visits before you move in unless you will be experiencing a zoning hearing. Instead, I would recommend being a good neighbor when you're moving in, as in your own home moves. Interact with the folks next door and across the street. Invite them in for coffee. Keep up your property's appearance. You must make the effort to be a real part of that total neighborhood and community.

be a good neighbor
2. If time permits, in the earlier stages, involve the community and its leaders in planning and developing programs. Unfortunately, very often programs develop when the "bread" becomes available and the planning is not as sophisticated as we would like it to be and know it should be. Get a prominent realtor to work with you. As the old saying goes, "it's much better to have them with ya than agin' ya."

community leaders
3. Recruit volunteers from political, civic, social and church groups. Screen and train them for meaningful roles. They can provide an outstanding opportunity for normal social interaction for your residents. They can be involved in recreation, cooking, sewing, grooming, first aid, transportation and as therapy aides, citizen advocates, friends and companions. But, do not exploit your volunteers! Protect them and respect them as valuable persons. Treat them with dignity as you would hopefully be treating your residents and expect to be treated yourself. Don't exhaust them. Inspire them and catalyze them. And remember, people volunteer for work (a cause) which excites them. If handled correctly, your volunteers can become your most significant force for social change in your community. If you're going to develop a meaningful volunteer program, then I would recommend a five-level training program.

volunteer programs

 - a. Pre-service training: This consists of a general orientation to the facility, your goals, your objectives and your policies.
 - b. Beginning skill training: This training emphasizes preparation for a particular assigned job. It must be a valid job and not busy work.

- c. Maintenance of effort training: This will be what perhaps we refer to as ongoing, inservice training; on-the-job training; refining, improving and sophisticating existing skills.
 - d. Periodic review and feedback: This training provides an evaluation of the relationships, an evaluation of the setting and an evaluation of the goals. Is it really working? Is it meaningful for both or all of the people involved?
 - e. Transition training: This is training for upward mobility or promotion, providing positive strokes and self-fulfillment. Don't lock a volunteer into the same job year after year. That's one way to turn them off.
4. Develop radio and television spots for public service announcements (PSA). These should be positive and constructive messages. Be careful of exploitation in your public service announcements and in your fund raising techniques. Braces are very commonly used to elicit everybody's sympathy. Kids are pawned - adults possibly - in the name of charity and fund raising. One approach that I'm aware of that I think is positive is "Project People" put on by a coalition of the Minnesota ARC, UCP and Epilepsy organizations. They have bumper stickers which say, "People who are retarded are people." "People who have epilepsy are people," and "People who have cerebral palsy are people." They have also developed some mailings and public speaking information that's going out to various clubs and organizations with a checklist return card. You can have somebody come and talk on one of 18 or 19 different topics. It looks interesting. I don't think they are far enough into it to know how it's working. But as a model, it's different, and it looks good.

Be creative, but do be careful about the charity. I would refer you to an article by Elizabeth Peiper in the January/February, 1975 issue of Exceptional Parent, in which she talks about "What price charity." She is the mother of a severely handicapped child. "In an age when my taxes have helped put a man's foot in the dust of the moon, I have been told it would be economically unfeasible to waste a doctor's

positive
public
education

time to get my son's foot on the ground. We have to challenge, not meagerly accept, such a schedule of priorities in a society in which we spend millions to study the origins of man. We had better question where he is going." I wish I had written that myself.

5. Work with the media to publicize your program and your successes. Do everything you can to ensure positive, constructive exposure of your program and of the residents being served by it. But remember, one negative or destructive story will carry an image much longer than a dozen positive stories. That is an unfortunate reality.
6. Develop cost benefit data as much as you can but don't get caught in the trap on every single model. Some human services cannot be directly measured in dollars and cents. We must keep our options open.

constructive
publicity

cost/benefit
data

In this regard, I wish to share with you a story about a young man I knew several years ago when I was rehabilitation counselor with the State Commission for the Blind. Juan was 14 years old at that time. He resided in a state institution and was classified as functioning in the severe range of mental retardation with a measured I. Q. of 28 on the Stanford-Binet. He possessed limited verbal skills and basic self-help skills. He was referred to us because of his crossed eyes (strabismus). His right eye was constantly turned out, and it detracted from his otherwise good appearance. Upon completing his ophthalmology examination, the physician recommended muscle surgery for cosmetic purposes only since there would be no way to restore vision in this amblyopic eye.

After much discussion among staff, evaluation of Juan's needs and a "counseling" session with Juan, the surgery was scheduled. The surgery was a success. Several weeks later I returned to that institution and went to Juan's dormitory. He ran toward me, took me by the hand and led me to the restroom. We then stood in front of the mirror and he said, "See. Pretty eye." The cost-benefit analysis of Juan's surgery cannot be measured in dollars

and cents. He was a new person with a stronger self-image and far greater peer acceptance. The surgery made a difference. He did know and appreciate the difference in his appearance, even with his low 28 I. Q.!

economic
contribution

7. Develop data about the home's contributions to the local economy as part of the real world. How much money is going into salaries? How much for food, rent, utilities, clothing, professional services, supplies, gasoline and all other expenditures in that particular facility's budget?

respect
privacy

8. Have tours or open house, but don't exploit your residents! Remember, it's their home. Ensure the residents' privacy and dignity during such visits. I think we have been abominable in displaying our community residences on five minutes' notice to anybody who happens to come into town, without any regard for the people who live there. The residents are not objects at which to gawk. They're people. I wouldn't want it. I don't think you would want it. Put yourself in their shoes. Let them be tour guides, if they so desire, and be sure that you have their permission to have a tour or an open house.

outreach
to families

9. Provide outreach to families - support services and respite care for children and adults at home in the community. Family involvement in program planning is a must. I couldn't agree more with Peg Gorham. If you're really doing a good job, a parent will tell you, and they will tell everyone else. On the other hand, if you're really bad, they will tell everyone else about that too.

teach
others

10. Provide training for staff in other agencies - specialized and generic - so that your residents have full access to their services. Assist in educating physicians, dentists, lawyers, judges, police, sheriff, etc.
11. Provide training in your facility for university students if they are in the vicinity. They are a part of your community, too.
12. Don't be afraid to enter the political arena, to rearrange priorities and the share of community resources available to retarded persons. But do this systematically and begin

by categorizing the existing services and the resources already going into those services. Budgets are made by people and if desired, people can, and sometimes do, change their budgets. But if you are going to get into a political arena, you had better have the persons and resources to follow through with the clout that you tell people you have, whether it's a positive or a negative reinforcer that you're planning to give to someone. If not, you will lose your credibility quickly. You need action plans or objectives.

politican
base

13. Don't be afraid of monitoring. Get involved in the accreditation process and invite neighbors to public meetings. Work with your ARC and other advocate groups. Pay particular attention to Section 3 on Community Organization in the AC/FMR Standards for Community Agencies (red book). Five of the seven sub-sections in Section 3 contain standards applicable to all agencies and reflect the critical need of organization and communication in community systems. You and your colleagues can develop objective behavioral criteria for entry to and exit from programs. We need to know what the requirements are to enter a facility, and what the criteria are for leaving that facility and moving on to another program more compatible with the needs of the individual. Four "C's" are important here: Concern, communication, cooperation and coordination.

accreditation

14. Prepare your residents for potential rejection and how to cope effectively and appropriately with it. We do poorly in this area. We also do poorly in this area as it relates to vocational rehabilitation. The research would probably fill this room about all the great vocational training that we can provide to and for people who are retarded. We know that persons who are retarded do not lose their jobs because of their skills; they lose them because of personal-social behavior problems. We still haven't, though, really implemented good techniques to eliminate that area of difficulty.

socialization

consistent
efforts

15. Don't get impatient and quit. Time, apathy, a history of dehumanization, the dominance of the medical model and ignorance are the biggest enemies of our retarded citizens. People create problems and people solve them. As the famous writer, George Bernard Shaw, said, "The reasonable man adapts himself to the world. The unreasonable man persists in trying to adapt the world to himself. Therefore, all progress depends upon the unreasonable man or woman."

During our recent history we have learned that it is usually the negative attitudes of the community, rather than the problems or disabilities of the individual, which make the adjustment of the retarded person to "normal life" particularly difficult. There are no magic rules to shape attitudes because all communities are at different levels of consciousness and have different needs, BUT,

I do know that with our concerted efforts more support will evolve in our communities and more persons we call retarded (or developmentally disabled) will be able to avail themselves of our human service systems and be able to live close to normal, dignified lives in our communities. Throughout this evolutionary process we must stand ready to constantly reassess needs and modify programs accordingly.

In closing, I will return to my opening parable. I hope we have determined some possible answers to some of the questions about things which might keep us from our mission. If I can futurize a bit with you, I can see that the terrain on which we seek to build the city is fertile. It looks penetrable, and it appears that there are paths to carry the supplies. We acknowledge that some of the paths are small and even fragile, but alternative routes are being explored. New tools are at hand, and efforts are being made to lift the shroud of secrecy among the wise men.

Administrative Issues

David Rosen

Actually, the only reason I was able to make this meeting today was that I had promised the executive office that in addition to attempting to present Michigan in a good light, I would also attempt to sell some cars, at least five cars, before I leave this conference. I can give you a better deal than Mean Mary Jean or Joe Gargiola.

For the first year or so in Michigan, my responsibility was to work with the architect in developing the physical plan of the facility. The initial proposal called for a 750-bed institution. The second plan called for 650 beds. The architect's drawings proposed prior to my arrival in Michigan were scrapped as the plan did not coincide with modern philosophy. The Director of the Department and I convinced the Legislature that we didn't need 650 beds, that 550 would be more than enough. We had also previously agreed that prior to the completion of the facility, every effort should be made to develop alternatives to institutional living in the community. Today, because of the success of our community programs, the need for a residential facility has decreased to the point where accommodations for only 96 residents will be constructed.

residential
needs
decrease

The residential complex will include an administrative and service center, in addition to a medical care unit for those requiring short-term medical services. This reduction in projected need by over 650 beds represents what can be accomplished through the development of a comprehensive community placement program. The bids are in, construction has begun, and we have a proposed completion date of 1976.

services
based on
individual
need

The Macomb-Oakland Regional Center serves a population of 1,600,000 in a two-county area located immediately north of Detroit and Wayne County, a population larger than the State of Nebraska. The present recession aside, Macomb and Oakland are two exceedingly fast-growing, affluent counties. The primary concept and philosophy of the Center is to provide appropriate developmental programs and services for each resident based upon individual needs. The retarded individual will not reside in the facility any longer than necessary. When suitable alternatives can be found, the resident will be returned to the community in a placement planned with existing community agencies -- in his natural home, an apartment, a group home, a foster care home or a well-regulated nursing home specifically for individuals that are mentally retarded. Each of these facilities will serve the individual only as long as his requirements dictate that he remain. The Center's community services division will, when necessary, augment those followup services provided by appropriate community agencies.

planned
integration

It is planned that the majority of residents in the residential center will be integrated into daily community programs operated by other appropriate agencies within Macomb and Oakland Counties. Residents will be enrolled according to their needs in public school programs, independent or semi-independent work situations, community workshops, adult activities and work activity programs. In essence, the Macomb-Oakland Regional Center will be a major component of the service system responsible for the planning and provision of services for the mentally retarded in the Macomb and Oakland County area. Michigan's mandatory laws for the handicapped provide distinct service advantages for its population that falls chronologically in the age span of 0-25. All people in this category must be provided educational services whether they be in a community facility or institution, regardless of the level of intelligence.

The uniqueness in the design of the Developmental Homes on the campus of the residential center is that the 12 homes are planned in duplex fashion. Each four-bedroom home will have a living room, dining room and activity room for eight residents - a marked contrast to the large

buildings often associated with the institutional image. We are projecting that the stay at the Center for the severely and profoundly retarded population which we will serve will range from one day to one year.

When I first arrived in the state three and a half years ago, there were 1,300 residents from Macomb and Oakland Counties residing in other state institutions. At present, there are approximately 600 still in the state institutions. Although we do not have a physical facility, we have the same responsibilities in our catchment area as do the institutions in the various regions of our state. We have found it necessary since August, 1972, to admit only 22 new residents to the Oakdale Developmental Center, an institution which has been serving as our backup facility. We have eliminated the waiting list. We are responsible not only for finding appropriate facilities in the community in which these people can live, but also for providing follow-up services when appropriate community agencies do not have the capability to do so. Not only have we been successful in developing alternatives to institutional care for those individuals residing within the institutions, but we have also been providing a similar service to those individuals in the community who require the residential setting outside their own home.

county
responsibility

At present, we have the responsibility to oversee the placement program of close to 800 people living in the community outside their own homes. It would seem that if the current trend continues, some people might suggest that we would put ourselves out of business not many years after the institution opens. That may or may not be a fact. Only the passage of time will tell. If this does materialize, the architecture is versatile enough for it to serve many other human needs. It would make an ideal planned community for the aged. Or better yet, it would make an ideal rest home for burnt-out mental retardation professionals. It now appears that a model for the institution of the future might be a service center with a variety of homes located throughout a catchment area as one part of a flexible system of residential services.

a flexible
system

The nursing home is the largest single placement setting in the United States for the mentally retarded leaving institutions. Although not widely publicized, it is a fact that nursing homes are the major recipients of the retarded placed from institutions. A national survey of all institutions in the United States (which I directed in 1972, as President of the National Association of Superintendents of Public Residential Facilities, in conjunction with Dr. Lawrence Callan

under the auspices of the President's Committee on Mental Retardation) confirms this fact.

nursing home
settings

Experience and observation of nursing homes servicing the retarded show in a national cross section that they range from unacceptable to those which provide quality programs. They also range from converted homes and other establishments to proposed programs; from converted homes and other establishments to proposed facilities to be constructed specifically for the retarded. In some states, although classified as nursing homes, many are more similar to group homes.

The wide divergence of interpretation of federal guidelines relating to nursing homes requires study in order that the retarded receive maximum protection and service.

traditional
services

Although some existing nursing homes are suitable, as for the geriatric mildly and moderately retarded person, the real challenge is the development of the "special needs" skilled nursing homes for the physically handicapped, severe and profound who no longer need the "global" service of the institution. These are the people, who, as institutional placement programs are accelerated, have been left behind. It should also be clearly understood that the "nursing home" envisioned is not a custodial facility but a special needs facility programmed to meet the physical, social and recreational requirements of each individual. Nor should it be implied that those people placed in nursing homes be "forgotten" by those who have responsibilities on a community or state level. Movement from the nursing home to foster homes and group homes is possible -- and with many, after achievement of physical health, mandatory!

classification
of nursing
homes

The State of Michigan in recent years established a new classification of "Nursing Homes for the Mentally Retarded." Under this system, in which our agency played an important developing role, the Department of Mental Health has responsibility for the selection of mentally retarded patients and the evaluating and monitoring of special programs in which the retarded are placed. Department of Mental Health staff is provided for full-time assignment and consultative service in special agreements with selected nursing homes. At least seven new nursing homes were planned and constructed by private enterprise, each in a different region of the state, for the severely and profoundly retarded requiring nursing care. The program of each home is monitored by the institutional superintendent in the catchment area in which the nursing home has been built.

If institutions are truly to appropriately reduce their overcrowded conditions and utilize community resources to better care for the retarded, the agencies which regulate nursing homes, both in the federal government and in the states, must be convinced by all related professionals of the necessity for a better understanding of the needs and requirements of the mentally retarded who also require nursing care. I do not mean to suggest that all retarded persons should be placed in nursing homes. There are many retarded persons, from the geriatric mildly and moderately retarded to those who are physically handicapped and severely to profoundly impaired, who could profit from living in an appropriate, well-regulated nursing home -- but not for life! It should be noted that staffing, construction and space requirements of nursing homes are strictly regulated in Michigan, whereas the majority of state institutions today would be closed if they were made to adhere to the regulations required of nursing homes.

strict
regulations

Two nursing home programs for the mentally retarded are being operated under special agreement with our Center. The program content concentrates on independent functioning in the area of motor development, activities of daily living, language development, social skills and preschool skills. Training is accomplished by combining in-house programs with community resources.

goals of
independent
functioning

Macomb-Oakland staff is assigned to a nursing home for every group of 25 residents. Following an individual assessment of each resident, training programs are designed to meet the specific needs of each person. Primary emphasis is given to the acquisition of daily living skills. Training techniques and programs initiated by the program instructor are taught to the nursing home staff through formal inservice training and on-the-job experiences. Complementing the in-house programs are a variety of self-support, community-based programs. A church school serves 30 adults weekly. Bowling programs using special equipment and bi-weekly swim and gym programs serve 50 children. Other special events are provided through community-sponsored activities.

inservice
training

To provide an outlet for graduates from nursing homes and as another alternative to institutions, we have developed a new category of family care -- the community training home program, with from one to three residents in a home. Over 200 people appropriate for the program have been placed in 100 homes. More are awaiting placement, however, and our goal is to have them all placed prior to the opening of the Center.

foster families

Foster care programs are not new; however, some new facets have been added to this program. Foster parents must attend a series of training sessions and provide an in-house, prescriptive training program for the residents. Community recreation and social programs have been developed and provided for them. The foster parents must keep records of program activities and adhere to the program plan which is developed jointly with our professional staff. A sliding fee schedule is applied to determine the appropriate remuneration for operating costs and services. The fee schedule ranges from \$12.75 to \$20 per day. This is composed of \$7 for room and board plus in-house training funds from \$6 to \$13. Purchase of services in the community above these amounts is permitted when required.

finding
foster parents

To encourage the development of the community training homes, staff members have contacted over 200 churches, schools and civic groups, have been on television more than 10 times and have made 15 public service announcements on radio. Roughly 400 newspaper articles describing the program have been printed, including indepth feature coverage. A series of newspaper articles on mentally retarded children in foster care who are now adoptable have been printed in "A Child Is Waiting," a column in the Detroit News. Over 200 other speaking engagements have been completed, to which has been added the recently developed slide presentation regarding the community training home program. Numerous public and private service agencies have been alerted to the program and have referred suitable candidates for foster parents to us for our client population. A family care training home manual has been developed by the staff and serves as a reference to assist supervisory workers in their day-to-day contacts with foster families in the program.

Group meetings for the natural parents of children in the community training home program began on April 1, 1973, and the meetings are led by Macomb-Oakland Center staff. These meetings attempt to familiarize the natural families with the goals of the program and help them deal with their feelings about being parents of a retarded child. In some instances, it is hoped that these therapeutic techniques may make it possible in appropriate cases for the child to be returned to his own home.

Monthly staff meetings are held which include social workers from all agencies who supervise community training homes in addition to our own

social workers. During these meetings, new information and mutual problems are discussed pertaining to the day-to-day supervision of the foster homes and the programs for the residents. Macomb-Oakland Center staff screen all potential residents for community training homes through visits to the various institutions for the mentally retarded. Working jointly with the supervising workers, Macomb-Oakland Center staff assist in matching the residents to the families. All community training homes are licensed and no more than three residents are encouraged in a home. The Macomb-Oakland Center staff, which includes 30 professionals in various disciplines, has been assisting individual foster parents as consultants in the areas of speech and hearing, self-care skills, behavioral management, health problems, motor development and dental needs.

consultation
to foster
families

Our agency has also been heavily involved in the planning and development of group homes in the two-county area. There are approximately 180 residents now living in group homes in the catchment area. Although these homes are under the direction of the Community Mental Health Boards and other non-profit interested organizations, major funding and monitoring responsibilities are the continued responsibility of the Department of Mental Health through the Macomb-Oakland Center. Consultative services in all areas, including the screening and referring of appropriate candidates for placement, is a responsibility of our agency.

group homes

Group homes, hostels or halfway houses are not new. Examples existed in the 30's, maybe before. Their expanded use and many different models throughout the country are extremely significant. They range in size from three residents to 30 and more. Some states place maximums at 12, others at 20, some have no maximum. Their architectural models also have a wide range, from the regular home to the especially designed house to the motel, boarding house or apartment -- from no program to highly sophisticated, intensive, community-integrated programs... from opportunities to graduate to less restrictive program to dead-end programs. In short, the same range of differences that exist in institutions exist in group homes with a few major differences. The group homes are usually not as overcrowded, and they are usually less regimented. As part of or closer to the mainstream of population, by being smaller than our stereotyped institutions, they certainly have the opportunity to and should provide a better total living situation than the institution.

I would like to close with the following remarks which I believe are essential for consideration in any program serving handicapped people:

least restrictive
setting

One of the difficulties in widening the exit from the institution is the pervasiveness of the notion that an individual, including the severe and profound, should remain within an institutional program until he achieves his full potential. In my opinion we have to discard this rationale. The mentally retarded, like each of us, will never reach their full potential, whether in an institution, community or even a private academy. They have the right to live, learn and reside in the least restrictive setting possible. Being enrolled in a good institutional program is not an acceptable reason for denying freedom.

No setting, community or institution, should be viewed as permanent. The setting that may seem appropriate today may be too restrictive tomorrow. If we continue to establish permanent solutions for the retarded, we will be as wrong today as were our predecessors who stated that the only answer for the retarded was permanent institutionalization.

accountability

At each point in the progression of transition from institution to alternative residence, a specified agency, a specified program within that agency and a specified individual within that program must be responsible for the provision of services -- must be held accountable for their quality. They must be answerable to the client or his advocate, parents, and other persons providing local resource supports. They should not be just "coordinators," "reactors," or "vendors."

reluctance
and delay

A major concern that I have is that too many professionals in the community are keeping a staunch vigil at the entrance to their domain. While there are many examples of good community programs, there really are very few, if any, where the community is providing for all its own population of mentally retarded. More frequently, the lament that, "We need more time to develop appropriate resources," and "We need more time to get prepared," is heard.

There is an irony to this lament in that the initial cries of outrage that institutions were being insensitive to the right of the retarded came from professionals in the larger community. Now, frequently, when this same citizenry is asked to take part in the deinstitutionalization, they beg off because of lack of preparation, funds, etc. -- Nobody can expect enough time or money, whether they be in an institution or community. It is not unusual to hear some professionals in the community ask instead that institutions modernize what they have and tell the administrators, "Not now -- the time isn't quite right. We're getting ready."

The mentally retarded who are entitled to the opportunity to live with the rest of us neither deserve this delay nor have the luxury of time to endure it.

Macomb-Oakland
Regional Center

CRITERIA FOR SELECTION OF MENTALLY RETARDED RESIDENTS
FOR SKILLED NURSING HOMES

1. Residents shall be mentally retarded with measured intellectual functioning of less than 50 I. Q. (Exceptions to I. Q. level may be granted by the Director of the Department of Mental Health only upon receipt of request with the rationale for the exception from the Superintendent).
2. Residents shall be medically infirmed, medically fragile and/or have incapacitating physical handicaps and disabilities which require that they receive on-going medical surveillance, medical care and services under the direction of a physician and 24-hour a day nursing care under the direction of licensed professional nursing personnel.
 - a. Residents can be of any age, infant through senior citizen.
 - b. Ambulatory residents must have a condition of being medically infirmed with a medical and nursing care problem to be eligible (not just physically fragile and require protective environment).

- c. Non-ambulatory residents with severe contractures, or at risk of acquiring contractures unless intensive physical therapy treatments and on-going skillful nursing care are provided (i. e., spastic cases) are eligible candidates.
3. Residents whose intellectual functioning is subnormal due to senility, cultural deprivation, or accidents which occurred after early childhood are to be excluded.
 4. The need for a protective living environment due to physical fragility is not a criterion for nursing home placement, in and of itself. (Residents who are physically fragile and require a protective, fully supportive environment may be cared for better, or as well, in a supervised sheltered living situation such as a foster/family care home).
 5. Non-ambulatory residents (a) who do not have a specific medical or nursing care problem, (b) who do not require care under the direction of licensed professional nursing personnel, (c) but rather require continuous basic physical care and (d) are dependent for life support services are to be excluded.

(For example, residents with severe physical handicaps whose immobility status is stable and would be essentially unchanged by professional nursing and/or intensive physical therapy treatments; are mobile via wheelchair, braces, crutches, floor wheel moving carts, etc.; require careful supervision and good basic physical care and life support services, rather than nursing care by licensed nursing personnel.)
 6. Blindness, deafness (or other sensory impairment) is not a criterion for nursing home placement in and of itself.
 7. If a resident's condition is suitable for, and it is determined that he or she could be placed in an appropriate family care home or group home, the resident should not be identified for nursing home placement.

Reactor Panel

ELEANOR ELKIN

I know you are all dying of hunger and everything else, but if I don't allow my people that have been taking notes for two days to have a little bit of reaction time, I think they're going to explode all over the room. I have mentioned to a couple of them during the coffee breaks that we will be cutting down on their time, and one of them said, "You're not gonna cut us out all together?" So, no, we're not but we do have to cut down, and I'm going to ask them real loud right now - they can each have between three and five minutes and the closer they make it to three, the happier you will all be and the less happy they will be. We have promised the gentleman who wanted to speak yesterday that he could have a couple of minutes in the end. I hope he'll cut his down to two, so you all won't die of hunger. I'll introduce you when you get up here.

This first lady is Rita Charron who is a mental retardation specialist from the Division of Community Services in Michigan; Dolores Norley who is Chairman of the NARC International Relations Committee; Joe Winters who is a member of the Board of Directors of NARC; and Henry Lynch who is the Director of Lynch Home, from whom you heard yesterday. I'm not going to try to moderate this except we'll hold up a time sign if it all gets too long.

RITA CHARRON

We've made a pact that we are going to make this short. As Eleanor has said, we are interested in preparing an NARC position that would define the potential of the nursing home in the service system for the retarded. Deinstitutionalization was a concept grabbed at by many state administrations. When people became sensitive to what good institutions' services should be, the costs of institutions went up. At the same time this was happening, we were talking about deinstitutionalization and state administrations, across the nation, jumped at this and began what we now call the "dumping" process. So, we are not only dealing with the potential of nursing homes, we are dealing with the correction process. We have many nursing homes loaded with retarded people inappropriately placed as a part of the deinstitutionalization plan. This also applies to the old houses in the inner cities that were used also to dump people from institutions. So in addressing ourselves to a position, we cannot ignore that many people were placed inappropriately as part of our well-supported deinstitutionalization process. We must find these lost people in our efforts to appropriately place and find services, and, as George Gray so well said, we must establish criteria for placement in the nursing home. As David Rosen said, if you establish the appropriate criteria, you find a very small number of people really needing nursing home care. All of the people who spoke in our two days have addressed themselves to the assessment of need, the establishment of goals, long and short terms, and to defining the approaches to meeting these goals. I believe they were saying that each person placed in any kind of residential facility must have a dynamic placement; that the services provided by the nursing home should be needed by that person that is placed there. It should not be used because it is the only alternative.

Also our position must deal with the right to treatment. We heard from Mr. Pottinger yesterday, and he did tell us that there was some fuzziness on the right to treatment, between people living under a public administration in a state institution or a publicly supported nursing home or residential care facility, and those living in totally private facilities, and that we needed to find out and make sure that this definition is cleared; that a person placed in a private institution discharged from state care also has a right to treatment.

In response to Mr. Rosen's recent statement regarding the social services system, he called to my attention the fact that, like Pat McNelly said, we have a lot of cars going in the same direction, maybe even attending

the same meeting or serving the same client, without regard for the guy in the next car and what he might have to offer. We must deal with money streams. In all of your states' social services systems or public welfare systems are very important money streams and we must determine how our mental retardation systems fit into those money streams. To use it; coordinate with it; join it in its car directed towards the care of that client is one of our most important challenges. We must coordinate our efforts with all money streams or agencies if we are to attain a good position. Thank you.

DOLORES NORLEY

We should have had with us at this seminar the author of a book I recommend to you: TENDER LOVING GREED, that expose of the problems of nursing homes.

I feel we've had a schizophrenic meeting. I heard people outlining all the difficulties which the misnomered nursing homes present; inappropriate surroundings, medical design when the resident is not in need of a medical rationale, hang-ups on hygiene in true medical heritage of caring more for a temperature chart than a loving hug for an abandoned human. Then the next speaker accepts the term "nursing home" as if it made sense and as if the people we are trying to move into the communities were honestly in need of skilled nursing care. And what the devil does "skilled nursing care" mean, anyway? Nursing is either skilled or it's lousy. Skilled is assumed.

We have been seduced by the money stream. We have been prostituted by the federal buck. We accept the use of those nursing homes for people who don't need them, and we use all those ghastly alphabetized abbreviations as if they were Holy Writ. They ARE Holy Writ if we've sold our souls for that mess of porridge for those for whom we advocate. That we have.

We use those magical ICFs, etc. (I wash my children's mouths out with soap for saying lesser blasphemies) because unless we use them we can't transfer monies--we are substituting state monies with federal monies. We have fallen into the trap of the nursing home operators. We play their game, use the terms their lobby has imposed on our laws and place our helpless charges in unseemly

living conditions--all in the name of the almighty buck. Then there is a self-fulfilling prophecy at work. Whether they need it or not, nursing is what they get, and it's all they get -- if they get even that.

Semantics determines, no matter what the original intent. Any experienced politician can tell you that. The moment we say "nursing homes" and accept Fed money for them, we are, by damn, going to have that model, no matter how inappropriate.

I am not going to react to each person, though I have notes on each. Phil will do it superbly. I shall be global in my response to the speakers. My response, overall, is that we have been took, and worse yet -- we have been took for people who can't speak for themselves.

We have been polite here. We have assumed rationality on the part of the government of the United States, on the part of the states, and on the part of nursing home operators. They don't really know a damn about retardation and its needs. How many people need bed care? About 99% less than institutions are giving, because of the ignorance of the doctors and nurses we listen to when they stamp out potential by dictating medical models. How many of those coming out of institutions need what we call nursing homes? Precious few. Remember those words: PRECIOUS FEW.

I recommend another book to you, to alert you to our seduction -- Tom Wicker's A TIME TO DIE, the story of the Attica prison atrocities and what went wrong. Why did it go wrong? Because he and others, he says, assumed rationality. For the love of God -- will we never learn? We assumed rationality when we almost lost our country in the name of "national security" coming from the mouths of evil men in high places.

What are we doing to ourselves? What are we doing to the people for whom we claim to be advocates? We are not being advocates. We are playing footsy with questionable companions, with nutty rules. And we don't seem to have the guts to say -- "Hey -- these rules don't make sense!"

We had a good M.D. speaker at this meeting. Put that in your memory book. It won't happen often in your lifetime. Jim Clements said all the right things -- with courage. Put them in your memory book too.

Henry said that all the solutions come from the private sector. He is absolutely right. The system cannot, by its nature, create new ideas. All new ideas come from the outside and are forced on it.

Susan had an absolutely marvelous presentation. It should be repeated. I remind you of one of her points: Remember that the regulations are not output measures. If you are going to remember only one thing -- remember that.

I shall remind you of three things in addition to remember. George Gray talked about Kushlik and the fact that there is no need for a nursing milieu except for a very, very few people. So few that you don't need a facility, or what we call nursing homes. If you could have the adventure of seeing the Kushlik experimental homes, where the worst multiply handicapped residents you have ever seen in any back ward are living and developing in normal homes in normal neighborhoods -- you would know he's right.

Gene's presentation on how to program last night was marvelous. It was not just a good program -- it was a learning experience. Shame on you who didn't come. I would guess, from experience, that those who were absent are having their way paid by someone else.

Combine that "how-to-program" with what Peg said so tellingly about the need for programs, then throw in something I'm writing for parents called, "Pretend you're dead" (pretend, then see how you'd work for a program for YOUR advocates), then perhaps we can look logically at the semantics we are corrupted by and get ourselves straight again.

JOE WINTERS

Dolores, you seem like one of those unreasonable people upon which progress depends. I'll try to be brief - in spite of having three pages of things to say.

In reacting to the entire conference, as well as the NARC Board meeting last week, one thought strikes me. Quite simply, NARC is out of money and, therefore, my conservative conscience tells me we must be sure full value is received from the excellent presentations we have heard today.

I suggest we collect the information and philosophies from this symposium, break them down into action plans that describe the problem

and prescribe a definite plan of action for those people most likely to effect the change.

I can't help but wonder how rural areas can and will relate to what was said here... have we anything for those who have nothing - or at best only a mediocre nursing home? We will need to be sure our recommendations contain some positive suggestions on how ICFs and nursing homes can improve their services to retarded individuals when they are indeed the only choice

We've said a concerted effort must be mounted to educate surveyors and nursing home operators to the fact that the needs of retarded persons are more social and educational in nature than medical.

It is not enough to educate ourselves and pinpoint the obvious problems. We must get the word to somebody who can help us do something about them..... via specific action plans.

Thank you.

HENRY LYNCH

Since I advocate providing services to retarded people and their families with a great deal of sensitivity, I'll try to be sensitive to you. Remember two or three ideas. First, lie down in a crib, look at a white ceiling. Imagine doing that every day of your life, every waking hour of your life. Second, put your head as far as you can to the right or to the left and try to swallow, or extend your head back hard under pressure and try to swallow. It's difficult. That inability to swallow is one of the reasons people are in institutions, historically. Those bad muscle patterns can be corrected, or at least ameliorated, if we care. Third, if you forget the first two points, and you ever visit my Home, I will request Jenny, who will be walking by that time, to throw you down the steps and turn on the sprinkler system. Thank you.

Comment

My name is Philip Vaughn, and I'm from Milwaukee, Wisconsin. I'm retired from Schlitz Brewery for three years - the beer that made Milwaukee famous. I'm a charter member of the Wisconsin Association for Retarded Citizens, UARC, and I'm a parent of a 32-year-old, profoundly retarded daughter living at Southern Colony. Phyllis has many physical defects, too, but she is receiving excellent care at Southern Colony. She looks good; her tone is good. I'm also in favor of mildly and moderately retarded persons being returned or discharged into their communities, into group homes. Since retirement, I do a lot of volunteer work for New Concepts Foundation, for establishing group homes throughout the State of Wisconsin and for the Jewish Vocational Service developing halfway houses for the mildly retarded.

parent
volunteer

I have been sent here to tell you that parents vehemently protest their severely and profoundly retarded children being discharged into proprietary nursing homes. I have a file here of newspaper clippings, collected in the last 14 months in the City of Milwaukee, covering nursing home problems and court violations. Listen to one or two headlines so that you get a tone of what is in the file: "The Inspectors Accuse Mount Carmel of 50 Violations - 20 of Them Are a Repeat From Over a Year Ago." "Lt. Governor Shriver says, 'There's a Chronic Noncompliance With the Nursing Home Codes'." These

protest
proprietary
nursing homes

are minimum standards that are not being met. In addition, I have with me a report issued in December of '74, by the Senate Subcommittee on Aging, covering nursing homes - 160 pages - replete with nursing home violations, court violations and problems. It says, "There exist physical injury, personal abuse of patients and life-threatening conditions in more than half of the 23,000 nursing homes throughout the country." And they continue by saying that, "It would make your blood chill."

"they don't
belong here"

I have visited many proprietary nursing homes and what I read in the newspaper and what the Senate Subcommittee says, I agree with. I have also visited the sectarian nursing homes in this area, the ones run by the Episcopalians, the Catholics, the Jews, the Lutherans, the Methodists, and I find an altogether different type of care. The motive is not profit. The motive is compassionate. I asked these operators, "Do you have any mentally retarded people in your home?" And they said, "No." And I asked, "Why not?" They said, "They don't belong here." And then I said, "Well, why don't they belong here?" To which they replied, " - because a nursing home is designed to take care of seriously ill people, to provide terminal care for older people. It isn't a place to spend a lifetime of living."

So, in the face of this preponderance of evidence of nursing home deficiencies, parents in my home community strongly protest nursing home placements. I think we should seriously consider these feelings in our deliberations right here and in the future, because this directly affects the delivery care system for the mentally retarded. I thank you all for giving me this time.

A Service System

Karen Green

The overriding issue we must address ourselves to in this conference is: "What is the role of the intermediate care facility in the continuum of services for the mentally retarded?" I would like to share with you some of ENCOR's experiences in the establishment of a specialized setting for severely and profoundly retarded multi-handicapped children. Perhaps one of the most important things we can do for one another is to share our mistakes more than our successes, so that others can avoid the same.

In the past, we considered it axiomatic that severely retarded individuals (with associated multiple handicaps) needed institution-based programs. Indeed, this became the rationale for admitting large numbers of such youngsters, very early in their lives, to large congregate care models within the confines of public supported institutions. After all, we assumed that the life expectancy of the majority of these children was too brief to provide anything but custodial care.

In spite of an increasing repertoire of techniques for facilitating growth in the child with a profound developmental delay, we have,

The speaker wishes to credit Camilla Allen for her assistance in preparing this presentation.

for the most part, failed to provide the human management systems necessary to make that growth a reality.

In Nebraska, the specialized residential program for medically complex, multi-handicapped children developed as one of the last components of a wide spectrum of services for the mentally retarded.

Evolution of Programs

In 1968, both the need and key concepts of a community-based residential continuum for multi-handicapped and severely retarded children were presented in the benchmark report of the Governor's Committee on Mental Retardation. Conceptually, the committee recommended that a series of "Maintenance of Life" units be established for those persons who are so impaired as to require medically-oriented services necessary to maintain life.

At that time, almost six years ago, it was widely believed that while the need for other residential services for retarded citizens would decline as non-residential services increased, the need for "Maintenance of Life" units would not diminish because the mortality rate was expected to remain constant.

Developmental Maximation Unit

The Developmental Maximation Unit was established in a wing of Douglas County Hospital in August of 1972 to serve those youngsters whose severe or profound retardation was complicated by medical difficulties (e.g. uncontrolled seizures, chronic and acute respiratory difficulties) and extreme motor challenges (e.g. cerebral palsy, scoliosis, dislocations) which rendered the children nonambulatory.

The Unit was conceptualized as a residence and was made as homelike as possible; it was initially also a school and provided an educational setting as close to an ENCOR Educational Center as possible. The Unit was set up to provide residential services to 16 multi-handicapped children. The children served were those typically found in pediatric intensive care units in general hospitals or infirmaries in institutions for the mentally retarded. For medical reasons, initially about half the Unit's residential clients remained at the Unit for day training programs; the other students were transported to alternative day programs in the community.

a place
for learning
and living

The children who were admitted to the Unit were first given an intensive medical work-up by the facility's consulting pediatrician as well as other medical consultants when appropriate. There were two purposes for the initial physical screening: (1) many youngsters coming from the institution had little or no reliable medical data provided; and (2) in order to establish significant learning objectives, we evaluated and intervened with the child's medical obstacles to growth and development. For example, a child who is seizing at a high frequency has very little energy or time left over for educational or social activities. A child with complete hip dislocation cannot be comfortably placed in an upright position so he/she may interact with the environment. A child with constant upper respiratory infections must spend a major portion of the time in isolation. These diagnostic services were provided to every child regardless of the degree of handicap or the prognosis from previous medical opinions derived elsewhere.

Because the Unit was located on a ward of the hospital, emergency medical attention was available 24 hours a day. Bright paint and carpeting, patterned draperies and children's furniture (not hospital beds) made the Unit homelike and warm.

The Unit staff was composed of a combination of education and nursing personnel:

- (1) Teacher - Monday through Friday - 8:00 a.m. to 4:30 p.m.
- (2) Teacher Asst. - Monday through Sunday - 7:00 a.m. to 3:00 p.m.
Monday, Wednesday, Friday - 3:00 p.m. to 11:00 p.m.
- (1) Teacher Asst. - Tuesday, Thursday, Saturday, Sunday -
3:00 p.m. to 11:00 p.m.
- (4) Teacher Assoc. - Monday through Sunday - 7:00 a.m. to 11:00 p.m.
- (1) L.P.N. - Monday through Sunday - 24 hours a day
- (1) Nursing Aide - Monday through Sunday - 11:00 p.m. to 7:00 a.m.
- (1) Housekeeper - Monday through Friday - 7:00 a.m. to 3:00 p.m.

Physical therapy, speech therapy and other adjunctive support services were provided on a consultative basis from either ENCOR or community resources.

nursing
care

The nursing staff was responsible only for the administration of medications and treatments ordered by the Unit's medical staff, providing direct nursing care to critically ill children and assisting both the Unit's physicians and other medical consultants in providing medical services to the residents.

health and
educational
activities

The majority of medical procedures which could be incorporated into the residential-educational setting were performed by the Unit's educational staff. The rationale for this approach was that many procedures which are traditionally assumed to be medical maintenance activities could be conceived instead as having direct implications to the child's overall educational program and could be incorporated as part of the educational day. For example, passive and active range of motion, postural drainage, therapeutic bracing activities and other such procedures were included as components of learning-oriented projects.

educational
priorities

Children whose needs dictated that they remain in the Unit during the day were provided training activities designated to help them move to more normative educational day programs such as ENCOR Educational Centers, Meyer Children's Rehabilitation Institute (University of Nebraska), integrated regular pre-school programs or adolescent education programs. Activities during the day primarily concentrated on large and small motor development, pre-language and speech development, eating and toileting control and social development.

Educationally, the major program goal was to foster the children's acquisition of self-help and gross motor skills. Educational priorities encompassed motor control, development of chewing, sucking and swallowing skills, improvement of gross motor skills and also the development of "tool skills" for language programs.

the IPP

Each child had a written individualized developmental program plan that specified the course of current and future motor, special sensory, cognitive, physical and recreational developmental goals. This plan was developed by way of the joint efforts of the child's parents or guardian and the ENCOR program staff and physician. The initial plan (IPP) was written up within 30 days of enrollment. These plans were established and reviewed at three month intervals. Program staff had the responsibility of continuously documenting and evaluating progress through the use of "Precision Teaching" techniques.

The following outline represents a description of a child's week at the Developmental Maximation Unit:

Monday Through Friday

- 7:00 a.m. - Rise and shine - Dressing programs
- 7:30 a.m. - Breakfast - Feeding programs, hygiene
- 8:30 a.m. - Off to school (for 9 children)
- 9:00 a.m. - Educational day - Gross motor programs, self-care programs, fine motor programs, language programs, socialization programs, medical monitoring programs (between 6-10 projects per child)
- 12:00 p.m. - Lunch - Feeding programs, motor programs, hygiene
- 1:30 p.m. - Nap (as age appropriate)
- 3:00 p.m. - Informal socialization activities - Socialization programs
- 5:00 p.m. - Dinner - Feeding programs, motor programs, hygiene
- 6:30 p.m. - Informal socialization activities, motor programs, socialization programs, hygiene, field trips
- 8:30 p.m. - Snack - Feeding programs, motor programs, self-care programs
- 9:00 p.m. - Bedtime (as age appropriate)

Saturday, Sunday and Holidays

- 7:00 a.m. - Rise and shine
- 8:00 a.m. - Breakfast - Feeding programs
- 9:00 a.m. - Informal socialization activities (with gross motor programs)
- 12:00 p.m. - Lunch - Feeding programs
- 1:30 p.m. - Nap (as age appropriate)
- 3:00 p.m. - Informal socialization activities
- 5:00 p.m. - Dinner - Feeding programs
- 6:30 p.m. - Informal socialization activities
- 8:30 p.m. - Snack
- 9:00 p.m. - Bedtime (as age appropriate)

community
adventures

Because of the need to provide culturally appropriate routines and rhythms, the children's activities approximated as closely as possible those routines experienced by normal children in the community; i.e., more informal activities on the weekends and holidays. Children were taken out into the community in small groups to restaurants, shopping centers, movies and to the zoo, etc., as often as possible. Through the use of a staff advocate system, most children were taken out "individually" into the community for an activity at least once a month. Also, parents are encouraged to take their children out in the evenings and weekends. If the child could not go, parents and siblings were allowed to visit at any time. Many parents took their children home for weekends and holidays.

progress in
living

Because the Unit provided a 24-hour, 7-day-a-week program and because no placement in the facility was regarded as permanent, "graduation" involved both educational and residential moves. The educational options were: segregated educational program for children or adolescents, integrated pre-school program, infant day care, infant home training, regular day start and public school. Residential alternatives were: the child's own home, small family residences and group residences.

"Graduation" did not have to be from the total program. Children did move out to the previously mentioned educational alternatives and continued to live at the Unit. Children moved to residential alternatives and continued for a while at the Unit's education program. Many have "graduated" from both.

problems in
the system

In spite of some modest success in the area of client movement, something in the system was not working. An analysis of the system brought out the following issues:

1. A benefit of a model such as the Developmental Maximation Unit was to provide (at the community level) a facility which negated the need to place children with profound and severe mental retardation, complicated by overwhelming physical and medical disabilities, into large institutional settings.
2. No similar model should be established without developing the movement alternatives concurrently. The initial assumption was that most youngsters would require an extended

period of time before they were ready to "graduate" from the facility. In actuality, several children initially admitted to the facility could have been placed directly into less structured residential and educational settings. Other clients required only three to six months before they, too, were ready to move out of a hospital setting. Unfortunately, alternatives were not available when the children were ready.

3. Mixing of children with wide variances in developmental needs tends to focus the program on the lowest common denominator. There were two distinct groups of youngsters residing at the Unit. One very small group (4 of 16) fell into a "high risk" category. At first, they required almost constant medical attention and a highly structured environment to stay alive. The other group did not require a hospital setting at all. Since the Unit staff was forced to concentrate its training and focus on meeting the medical and maintenance needs of the smaller group, the other children were only provided with "adequate" developmental growth opportunities. The primary goal for the "high risk" group was to provide them with the support systems (i. e., range of motion, postural drainage, etc.) necessary to move them out of the "high risk" category so they were medically independent. The larger group was medically independent almost from the beginning. The primary objective of the staff was to provide learning opportunities for this larger group within the five major curriculum areas (language, gross motor, fine motor, socialization, self-help) to facilitate movement.
4. Staff were forced to assume multiple identities: teacher, parent-surrogate, friend, paraprofessional, medical. This resulted in too high staff turnover, and a great deal of verbalized frustration with the task of "being too many things to too many people."
5. Parents found it extremely difficult to accept the movement philosophy because their children had always participated in a rigorously structured 24-hour environment (i. e., institution, hospital to Developmental Maximation Unit).

Change in Administrative and Program Structure

In the Spring of 1975, the administrative structure of DMU changed. The residential component was relocated for administrative supervision in the Residential Division. The education component was retained by the Educational Division (previously both were supervised by the latter).

With these changes, the DMU is to be regarded as a residential program only. The purpose for this change was to facilitate the transition to and from other residential programs and the perception of this unit as not a closed system (24-hour service) but rather as a specialized short-term support service for the rest of the residential continuum. Consequently, children staffed for this unit are now simultaneously staffed for the next step in the residential continuum. The responsibilities of the Education Division changed greatly. Since the Unit staff identity changed to that of residential personnel, they were no longer to be perceived as teachers. Those children who were capable of going out to other day programs continued to do so. Those children whose medical conditions dictated the need to remain in a single environment for a short time receive their educational program through Itinerant Resource Teachers. The Itinerant Teacher is assigned from the program that the child will move into when the medical situation stabilizes. For example, if the child is an infant, an Itinerant Teacher from the Infant Program is assigned.

The primary purpose for this administrative change was to change the perception of the children served by this unit. An individual served in a 24-hour closed system with a heavy medical overlay, and only secondary services coming from that system (i.e., recreation, transportation, speech therapy) reinforces the self-fulfilling prophecy... "How could this person possibly survive anywhere else." This prophecy extends itself to parents, medical professionals, staff outside the service, citizens in the community and eventually staff within the service itself.

This phenomenon results in an interpretation of the client as "not capable" or "can't make it." Developmental growth takes place in the home (residential environment), the school (educational environment) and play activities (social environment). A system which combines these environments can be defined as a "closed system." The closed system can stimulate developmental growth. Unfortunately, however, the closed system indicates that the individual is less than, is deviant, is not capable of benefiting from environments experienced by his non-delayed peers. It is these perceptions which become the major obstacles to

need for
an open
system

perceptions
of the
system

effects of
a closed
system

developmental growth. The majority of the time the problems of the system are inappropriately projected upon the client so that he becomes someone to be "maintained" by society rather than an individual who is a developing human being. The change simply says that every child is capable of developmental growth and plans must be structured to provide for that progress from the beginning.

development
is continuous

By structuring a system that assumes and expects growth to occur in every individual served, separate single purpose environments are utilized. When combined, these programs add up to a continuum of services which demands growth. Consequently, what appeared to be just an administrative change actually resulted in a major perceptual reinterpretation of the clients served.

Summary

Philip Roos

In preparing for this erudite presentation, I referred to the very excellent materials prepared for us, and I leaped immediately to the glossary to find a definition of nursing homes. Imagine my frustration when I could not find such a definition. One of the great difficulties, I think, with this issue is that I am not sure we know what we are talking about.

It seems we are talking about at least three different types of facilities - the skilled nursing home, which, as we have heard, is primarily a medical facility for acute medical problems; a facility in which there are very few mentally retarded persons, a facility about which we are not particularly concerned. Secondly, there is the intermediate care facility, the ICF, which, as we have heard, deals essentially with the somatic, that is the physical, needs of the residents. We have heard that mentally retarded persons may occasionally be placed in such facilities, but that they are not designed to meet the particular needs of retarded persons. And third, we have the ICF/MR, the intermediate care facility for mentally retarded persons. This seems to be the facility with which we are primarily concerned. This is not a medical facility. Jim Clements, as I recall, made it very clear that we are dealing essentially with a facility which focuses on developmental programming. That seems to be the most important characteristic of the facility. The

types of
facilities

fact that it is defined as an ICF/MR is essentially a function of the intensity of this developmental programming.

semantic
issues

The first issue, then, which strikes me is whether or not we are not dealing with a semantic problem. I think Dolores Norley (who is gone now so that I can speak freely) did, mind you, in her caustic remarks, allude to this issue. Her point was very relevant. Perhaps the very term "nursing home" is inappropriate. Certainly it seems to have many connotations which disturb many of us. We are not dealing primarily with a medical or nursing service, but rather with a habilitation developmental service when we refer to an intermediate care facility for mentally retarded persons.

There is no question that there is great interest today in this whole area of intermediate care. This seems to be a product, first, of a genuine search for better services for mentally retarded persons. Secondly, it is the product of a search for better funding - money. Dolores referred to it as "prostituting" (which I suspect is a profession like any other) and perhaps that is what we're doing. I'm not sure. We have heard, however, that the intermediate care facility for mentally retarded persons may indeed cost more than the so-called "skilled" nursing home. Third, the interest in nursing homes seems to be in part a product of our attempts to comply with the law, our attempts to escape litigation, to which Stan Pottinger referred.

Let me turn now to a subject which is near and dear to many of you; namely, anxiety. Obviously many of you carry a great load of anxiety with you throughout much of your life, as attested by your prolific smoking which has already been commented on. We have also heard ample evidence that nursing homes do present serious problems. Indeed, this symposium was called with a real feeling of urgency. Urgency that the National Association for Retarded Citizens, as the advocate group for mentally retarded persons in this nation, must address itself to this issue now. What are some of the problems? Well, we have heard many of them enumerated. Let me try and list them for you in a nice little "laundry" list:

inappropriate
placements

- First, there is the danger of a super-simplistic solution to the problems of institutions. We speak a great deal about deinstitutionalization, but Jim Clements said that deinstitutionalization was being corrupted, and he characterized it as a "multi-million dollar disaster." We have heard about the so-called "dumping" phenomenon - a phenomenon which, perhaps, has been fostered again by litigation. Stan Pottinger recognized

this possibility. As the lawsuits threaten, it is very tempting to de-escalate the institutional population by dumping the residents into other types of facilities. Funding streams and the proclivities of federal legislation and regulations have also played their part in shifting residents from one setting to another. The product of dumping is already with us. We have heard, for example, Rita Charron describe inappropriate placements already found in nursing homes or intermediate care facilities.

- A second major problem is that nursing homes and intermediate care facilities have the same basic problems as institutions - the same basic problems. Jim Clements referred to my excellent analysis of problems in institutions and claimed this analysis was equally applicable to many nursing homes, including the problems of dehumanization, of conditions fostering regression in the victims and self-containment. Allan Bergman spoke of the isolation from the community which can occur in a small facility as well as it can in a larger one. The problems of health and hazardous conditions, and even the potential exploitation of residents, may exist in the nursing home. Major problems have already been documented. Jim Clements spoke of several personal experiences which sounded just as horrible as some of the horror tales which have been described in institutions. Stan Pottinger spoke of the GAO survey which is going to generate, he tells us, some very disillusioning data. Indeed, I am told that litigation is now pending in two states which will be directed against institutions (that's not new), but at the same time, against community-based residential facilities as well (that is new).
- Next, we have heard that many institutions have been inappropriately licensed to qualify for the intermediate care facility monies. We have also been told that it may be inappropriate for all institutions to attempt to upgrade themselves to meet the ICF/MR standards. Susan Weiss suggested that a careful evaluation should be undertaken for each institution to determine whether or not it is desirable and cost beneficial to modify that institution to meet the standards. There are problems inherent in this question. For example, we are reminded that it might require massive amounts of money to bring up some institutions to standards, money which might be better invested in other alternative residential situations. At the same time we were warned not to abandon the institutions, to recognize that there is indeed a need to upgrade many of the institutions and that many can be upgraded successfully.

same basic
problems

certification
of the ICF/MR

inappropriate
placements

- Another danger which was discussed was the placement of retarded persons in general intermediate care facilities to avoid the more stringent standards required by the intermediate care facilities for the mentally retarded. This, obviously, would lead to inappropriate placements and to depriving these individuals of necessary programming.

medical
models

- We also heard about problems which are inherent in the medical orientation which still typifies the nursing home situation. Susan Weiss described to us the Congress, the states, the Medicaid program, the PSRO's, just to mention a few, who are strongly imbued with a medical orientation and who will need some educating to understand what is really meant by the ICF/MR regulations.

conflict of
interest

- We were also warned that many of the surveyors and the independent professional review teams may be totally naive about mental retardation and the needs of mentally retarded persons. We were further told of improper surveying procedures and the fact that surveyors themselves have told us that they are, at times, put under a great deal of political pressure to certify inappropriate settings. Many of these unfortunates are in conflict-of-interest situations.

decreased
state funds

- Next we were told (and I hope you will notice that we've had a lot of bad news in the last day and a half, ladies and gentlemen) -- next we were told that the intermediate care facility funds are replacing state funds in many instances, vitiating the basic goal of the program, which is to improve the quality of services.

monitoring

- Concern was also expressed about monitoring, about accountability, about a clear focus of responsibility. The dispersal of services makes these problems more serious. Dave Rosen expressed his concerns regarding the potential fragmentation of services, the lack of follow-through and follow-along services.

irrational
systems

- And finally, I believe it was Dolores Norley who insisted that we make a serious mistake when we assume that we are dealing with a rational system. She warned us that the system is irrational and that we should take this into account.

In spite of these problems and difficulties and potential dangers, we have also been presented with evidence which suggests that intermediate care facilities do present potential advantages and may, indeed, be appropriate and desirable alternatives. For example, we were told of their potential flexibility, of new models, of new ways of deploying staff, such as trans-disciplinary teams. Henry Lynch spoke of flexibility in administrative

modes, in different types of environments, in dispersed apartments and such like. The whole issue of smallness and dispersal was re-emphasized repeatedly, particularly as these characteristics tend to enhance normalization and individualization. A potential advantage is the possibility of grouping clients in different ways, such as in complementary or symbiotic relationships as suggested by Dr. Boggs, or the companion programs as discussed by Dave Rosen. George Gray spoke of advantages inherent in dealing with the private sector. And then earlier today we were presented some very encouraging models of what is already being done in intermeditate care facility settings. And indeed some of these examples are encouraging and could serve as prototypes.

evolving
systems

Throughout our discussion, ladies and gentlemen, I was delighted to hear that the basic principles advocated by the NARC consistently surfaced as being fundamental to good services to mentally retarded persons, regardless of where these services might be delivered. These principles, you will recall, include a developmental model of mental retardation which includes a movement toward progressively less restrictive alternatives. Dave Rosen spoke eloquently of the concept of transitional placements or short-term placements, as the individual is moved from one service to the next, so that the intermediate care facility is not a permanent home but a way station on the way back, hopefully, to the community. The whole concept of the individual program plan is, of course, intimately related to our concept of the developmental model.

a developmental
model

The principle of normalization again is inherent in much of what has been said. I was particularly interested in Peg Gorham's comments regarding the importance of furnishing normalizing possibilities to parents of mentally retarded persons. We have a great tendency to wax eloquent regarding our clients while we massacre each other; so that while we speak of treating retarded persons with great dignity, we sometimes fail to do so with non-retarded persons. Peg's comments regarding normalization and the need for community support of parents so that their existence can be normalized were most appropriate.

normalization

One of my very favorite principles is the principle of individualization; that is, the need to recognize the uniqueness of every person. I think it was Henry Lynch who began his remarks by stressing the importance of maintaining humanity and recognizing the individual client as the focus of our attention.

individualization

self-
actualization

And finally, the principle of self-actualization was certainly evident in what was said. I have defined this principle as the recognition that each mentally retarded person should be given maximum opportunity to determine his own course, to shape his own destiny, to make his own choices. Marie Moore, as I recall, in some of her descriptions, stressed the importance of the participation of the retarded person even in the assessment process.

I want to turn now, and you will be delighted to hear that I am moving rapidly toward an eloquent conclusion to these remarks, I want to turn now to a consideration of potential actions, picking up on what Joe Winters said to us, - that after all, the rhetoric is lovely, a balm to the ears, but action is what counts. I have attempted, then, to cull from these presentations some recommendations. Many of these were made directly by the symposium participants. I have inferred a few of them from the presentations. Let me just list these for you:

right to
treatment

- We must ensure that deinstitutionalization not lead to further dumping. The right to treatment includes preparing an institutional resident for community life, and it includes adequate alternative services. Stan Pottinger emphasizes this point, and if you'll recall, he underlined the fact that when the Department of Justice enters into consent decrees, these decrees incorporate this concept. The individual does not lose his rights when he leaves the institution for another type of facility. We must maintain our efforts to improve the quality of our institutions. It is very important, I think, for us all to be very clear that interest in intermediate care facilities, interest in group homes, interest in apartment living, interest in independent living does not vitiate nor negate our interest in and commitment to improving institutions. Indeed, the ICF/MR program and the funds associated with it can be a strong incentive for institutions as well as for so-called nursing homes, to upgrade their services and to develop comprehensive habilitation, developmentally-based programs.

legislation

- In referring to standards emanating from court decisions, such as the Wyatt case in Alabama, Stan Pottinger made it clear that these standards are developed with regard to a specific case and a specific institution and that it would be an error to legislate such standards into law. Indeed, he warned us that the law must remain flexible.

regulations

- Speaking of legislation, George Gray suggested that we press Congress to delete specifics of the Life Safety Code from the Medicaid statutes for intermediate care and skilled nursing home facilities, and that instead, these standards be implemented through regulations.

- We should also consider legislation which would establish a statutory basis for the Justice Department to enter into litigation on behalf of mentally retarded persons. Right now the Justice Department is taking a very "gutsy" stance in this issue. There is no clearcut legislative basis for their direct involvement as plaintiffs in these cases. litigation

- We may need legislation to ensure maintenance of effort through the ICF/MR program. Jim Clements shared with us his concern that the ICF funds were being used to simply replace state funds. Current legislation does not prohibit this. maintenance
of effort

- George Gray suggested that NARC develop a position regarding admission criteria for admission to intermediate care facilities.

- We were told by a number of our participants to develop proper monitoring procedures for intermediate care facilities by independent advocate groups, and that, ladies and gentlemen, I consider to be a direct challenge to the ARC movement; for who is better equipped to serve as an independent advocate than the ARCs? It means, however, that the ARCs will need to develop expertise in monitoring such facilities and such programs. monitoring

- Speaking of monitoring and advocacy, it is also amply evident that the advocacy function must be related to the assessment process and to the programming process of individual retarded persons. Indeed, Ms. Moore, Ms. Gorham and several others spoke of the importance of involving families in the planning of the IPP and in the assessment process. family
involvement

- The recommendation was made that HEW be requested to conduct a study regarding the enforcement and the effectiveness of regulations. Frankly, we need data. We do not have data; apparently nobody has data now, as to the effectiveness and current status of the intermediate care facility or the degree to which the regulations are being implemented. effectiveness

- Turning now to a different type of problem, it is obvious that there is urgent need to adequately train the surveyors of intermediate care facilities so they are well familiar with the issues of mental retardation and with the nature of programs needed by mentally retarded persons and so that they are able to interpret the regulations wisely. surveyors

It is equally important to ensure that these surveyors are free from conflict-of interest situations. Susan Weiss challenged us to evaluate survey findings so that when we consider them to be invalid, we contest them - we challenge them. This is part of the advocacy function.

- And finally, it appears to me that we should give serious consideration to the obvious semantic problems surrounding the whole issue of nursing homes, ICFs, ICF/MRs, all these other good things, so that we know what we are talking about. Possibly we need a new nomenclature for the ICF/MRs.

new
nomenclature

To conclude...that cheers your ears, ladies and gentlemen. Can't you see yourselves leaping on an early plane, out of this lovely city?To conclude, this meeting has essentially been a "sensitizing" meeting - a meeting designed to sensitize us to problems, big issues, the concerns and the challenges of this rapidly expanding arena. We obviously do not yet have all the solutions. Obtaining and developing them is part of the challenge. The principles of good programming, it is obvious to me, are constant. They apply to any setting. We must assure the legal rights and the human rights of the client wherever he might be, whether it be a nursing home, skilled nursing home, intermediate care facility or institution. The placement of an individual in any particular setting must be a function of that individual's need at that particular time. Period. Not the function of fear of litigation; not the function of funding streams; not the function of the "chicken syndrome....."

The decentralization of services does hold promise. It also holds threats. There will be greater difficulty in monitoring and in accountability. As a result, it seems crystal clear to me that we need stronger advocacy today than ever before at all levels - at the community level, the state level and the national level. We are entering into a new age of opportunity. Let us rededicate ourselves to making sure that it is an age in which mentally retarded persons fully enjoy the basic principle on which our nation is founded...freedom and justice for all...equality of all citizens.

Workshop: The Individual Program Plan

Gene Patterson

DEFINITION:

The individual program plan is a written plan of intervention and action that is developed, and modified at frequent intervals, with the participation of all concerned. It specifies objectives and goals and identifies a continuum of development, outlining projected progressive steps and the developmental consequences of services.

(AC/FMR Standards for Community Agencies)

PRINCIPLES:

An individual program plan should be developed for each person accepted for service, regardless of chronological age or developmental level. The plan should be based on individual assessment data and on other data that assist in understanding the client's situation, and it should be developed by the relevant staff of the agency (facility) serving the client, with the participation of the client and his family. A plan developed prior to the onset of services by the agency should be reviewed and updated, so as to meet the current needs of the client. Long and short-term objectives should be stated separately and within a time frame, and they must be expressed in behavioral terms that provide measurable indices of progress, and that enable the effectiveness of interventions to

be evaluated. Modes of intervention for the achievement of the stated objectives must be specified, and agencies capable of delivering the needed services should be identified. The individual program plan must be modified as goals and objectives are, or are not, attained. Review and appropriate revision of the plan must be a continuous and self-correcting process. The plan must help all concerned to coordinate their efforts and activities, so as to maximize services to the client.

(AC/FMR Standards for Community Agencies)

Workshop Objectives

1. Discuss program advantages and benefits of the transdisciplinary approach to three developmental tasks (self-concept, communications and mobility).
2. Develop an individual program plan covering a 7-day period, based on the individual assessment data provided in the workshop.
3. Identify the consequences to development in other cognitive and motor skills areas by a focus on the three tasks noted in Objective #1.

Considerations in Goal Setting

The overriding goal of a residential program is to foster those behaviors which maximize the student/client's human qualities by increasing the complexity of his skills and enhancing his ability to cope with his environment.

Setting appropriate goals takes into account the inherent logic of individualized programs; that is, providing an environment which enhances the logical sequence of behaviors and always builds upon previous learning.

- One must carefully consider the issues of phenomenological programs--those designed to produce specific behavioral phenomena without regard

for the logical sequence of behavioral patterns--versus developmental programs. Phenomenological approaches all too frequently ignore the long term consequences of programming in favor of short term gains. For example, the effectiveness and simplicity of behavior modification techniques can easily lead to their misuse if long term goals and ethical concerns are not carefully explored.

Those who reject all behavior modification techniques are equally short-sighted since these approaches can be utilized in highly developmental ways--providing we understand the consequences.

Developmental programming takes into account the sequence of behaviors and the nature of the individual learner. Consider, for example, those individuals who are profoundly retarded. They must spend a life-span with specific neurological insults. Long-term objectives for these individuals must be developmental, and they must also be attainable.

Objectives for the profoundly retarded person will take into account the ability to make choices, the opportunity to achieve mobility of some sort and the ability to communicate with sufficient skill to develop human relationships and to break down the barriers of isolation. The walls of isolation, within which so many retarded people exist, must be broken down or those individuals will have no opportunities for any degree of personal autonomy and intellectual development.

The retarded person, no matter how severe his disability, has a right to begin to determine personal likes and dislikes and to exercise some control of his immediate environment in order that his essential humanity can emerge.

Severely and profoundly retarded persons are often dominated by primitive sensory-motor behaviors. Programs, therefore, should develop behavioral patterns and cognitive operations to move the student/client into more concretely operational behaviors and the development of constructive self-concepts.

In assessing the learning needs of the profoundly retarded and/or multiply handicapped individual one can become totally overwhelmed by the global nature of his learning needs. If some sort of attentional focus is not called into play, the parent or professional is frustrated and rendered helpless to employ his skills to help that person. Much of group or gang programming probably results from this type of frustration.

Where the learning needs are so global, the focus should probably begin with an assessment of what the individual student/client can do.

1. Motor competency (What can he move and how efficient is the movement?)
2. Neuromotor assumptions (How much control does he seem to have over his motor behaviors?)
3. Sensory activity (How does he use his eyes, mouth, fingers, etc., and what evidence is there to suggest favorite routes of sensory input?)
4. Perceptual competency (What does he do in response to various stimuli, such as voices and sounds, objects, your face and hands, various tactile stimuli, odors and gross handling such as holding, stroking, hugging, cuddling, etc.?)
5. Problem solving (Does he reach for objects, turn toward sounds, respond verbally...?) At more sophisticated levels, does he use tools in any way (to pound or bang, to hold or retrieve, to feed himself, to amuse himself?)

Is he able to solve even the simplest puzzle, such as locating or indicating the location of a hidden object, or follow directions (at what level of competency?)

Writing Program Plans

Both the AC/FMR Accreditation Standards and the Federal ICF/MR regulations require an individual program plan for each student/client. The program plan must include specific goals and objectives which are subject to regular evaluation.

GOALS are broad, general statements of program intent.

- Goals benefit the client because they provide direction for program development.
-

- Goals benefit the staff because they provide the basis for a coordinated effort.
- Goals inform the public because they are the tools of communication, telling the public of program intent.

BEHAVIORAL OBJECTIVES are descriptions of learning outcomes which include an observable behavior, a criterion and the conditions of performance.

- Behavioral objectives benefit the client because they provide a basis for evaluating individual learning.
- Behavioral objectives benefit the staff because they provide a basis for evaluation of staff effectiveness. Objectives also aid in the selection of instructional activities and materials.
- Behavioral objectives inform the public and other professionals because they communicate clearly what is to be learned.

Task #1:

Recall that a behavioral objective has three distinct parts--an observable behavior, a criterion, and a condition. The "observable behavior" is usually fairly easy to identify, but staff members are often confused about criteria and conditions. Examine the two charts, taken from the Padzensky and Gibson book, Goalguides, to familiarize yourself with the elements of criteria and conditions.

Read the following behavioral objectives and

- a. place one line under "observable behavior,"
- b. place two lines under the "condition,"
- c. place parenthesis around the "criterion."

Example: Sam will reduce hitting behavior (to zero)
observable behavior *criterion*
whenever he is in a free play situation.
condition

1. At a distance of five feet, learner will toss a beanbag into the container, in four out of five trials.
2. Given pictures of ten different vegetables, John will name them within one minute.
3. JoAnn will grasp an overhead bar and raise her body sufficiently to allow a piece of paper to be slipped under her buttocks.
4. Using a 10-item vocabulary list, Mary will accurately match the spoken word with the printed word, 90% of the time.

CONDITIONS CHART

1. Time

- Examples:
- within 20 seconds
 - at regular intervals
 - in the class period

2. Allowances

- Examples:
- using paper and pencil
 - with assistance
 - given a number line

3. Restrictions

- Examples:
- without assistance
 - from memory
 - without losing balance
 - voluntarily provides information

4. Combination of Time, Allowances and Restrictions

- Examples:
- voluntarily provides information
 - from memory and using pencil and paper
 - only when asked and within the class period

CRITERION CHART

1. Per Cent or Number Correct

- Examples:
- 80% of the time
 - 4 out of 5 correct
 - within 90%
 - at least 6 times
 - answers at least once
 - successful each time (100% easily implied)

2. Time Limits

- Examples:
- immediately
 - within 5 minutes
 - during the following week

3. Qualitative Descriptions

- Examples:
- grammatically correct
 - neatly enough not to require revision or doing it over
 - extensiveness of vocabulary determined by the teacher

*Taken from: Padzensky, H.R., and Gibson, J.
Goalguide: A Minicourse in Writing Goal and
Behavioral Objectives for Special Education.
Belmont, California: Fearon Publishers, Inc.,
1975. Used by permission.*

Task #2:

Using the assessment data provided, write at least three (3) program objectives for a 7-day period. The objectives should be directed toward developmental needs in the areas of:

Self-concept

Communications

Mobility

1.

2.

3.

Task #3:

Outline a program plan which covers a 7-day period and is directed to meeting objectives developed in Task #2.

In this exercise it is not necessary to list all details of the prescribed activities--an outline is sufficient. Remember, however, that your outline must be detailed enough to permit easy expansion into a complete program plan.

Be sure that your plan indicates a clear sequence from point A (client's current skills and status) to point B (where you expect the client to be in 7 days).

164

Task #4:

Using the "Structure for Program Planning" (Page 167) indicate how your program outline relates to each of the developmental needs.

STRUCTURE FOR PROGRAM PLANNING

165

DEVELOPMENTAL NEEDS

ACTIVITIES

[illegible]

Adapted from: Hainsworth, Peter K., et al.
Project First Step, 1970. Meeting Street School,
 Providence, Rhode Island.

A Position
Statement
of the
National Association for
Retarded Citizens

NURSING HOMES IN THE SYSTEM OF
RESIDENTIAL SERVICES:
A POSITION STATEMENT

As efforts are made to reduce the size of public residential institutions, state planners and administrators have sought available options for the placement of mentally retarded persons into smaller decentralized facilities. The availability of federal Medicaid funding, plus increasing pressures to reduce institutional populations, have resulted in many retarded persons being placed in nursing homes and intermediate care facilities.

The purpose of this document is three-fold:

1. To identify specific problems associated with nursing homes and intermediate care facilities as residential programs for mentally retarded individuals;
2. To establish a series of statements which reflect the National Association for Retarded Citizens' position on the issues; and
3. To enunciate basic guiding principles which can be used by parents and professionals to assess the appropriateness of nursing home settings for mentally retarded persons.

Definitions

The term "nursing home" is used to describe a facility licensed as such by the individual states according to individual state definitions and criteria. That is, the type of facility designated as a nursing home may vary from state to state.

Nursing homes provide different categories of nursing care, but there are two basic types of nursing homes:

1. Skilled Nursing Facilities (SNFs)

These provide continuous nursing services on a 24-hour basis for convalescent patients. Registered nurses, licensed practical nurses and nurses' aides provide services prescribed by the patient's physician. Emphasis is on medical nursing care with

restorative, physical, occupational and other therapies also provided. This type of facility is recognized by both Medicare and Medicaid programs if a physician says such care is needed.

2. Intermediate Care Facilities (ICFs)

These may provide regular medical, nursing and social services in addition to room and board for persons not capable of fully independent living. ICFs are for persons requiring less intensive nursing care than that provided by skilled nursing facilities. Medicaid programs in most states pay for intermediate care.

A category of ICFs is referred to as Intermediate Care Facilities for the Mentally Retarded (ICF/MRs) and as such are subject to certification by a separate set of regulations. These regulations are differentiated from general ICF regulations by their focus upon the total developmental needs of clients with mental retardation or related disabilities, rather than just medical and nursing needs. A facility is required to meet the ICF/MR regulations based on the proportion of mentally retarded clients accepted in the program. Although the ICF/MRs are often referred to as nursing homes, the latter term is misleading because the federal definition embraces a variety of residential settings.

In considering the following position statements, the reader should note that the term "nursing home" is defined as separate from the ICF/MR program.

Basic Principles

The National Association for Retarded Citizens has periodically enunciated and endorsed certain basic principles which must govern the delivery of special services for mentally retarded persons. These basic principles* are abstracted here to illustrate their relevance to the use of nursing homes or intermediate care facilities.

The purpose of any residential facility is to assist residents in achieving and maintaining their fullest independence and ability. This role requires an aggressive and organized effort, focused on an integrated, individually designed program directed to achieving measurable behavioral objectives. The program environment must approximate as closely as possible the patterns and conditions of

*The reader is directed to NARC Policy Statements on Residential Services (1968) and the Handbook for Residential Services Committees (1972), for details of these principles.

everyday life in the mainstream of society. Above all, the residential facility must look outward to the larger community and must seek always to foster and strengthen the ties of its residents to the social life of the community.

The most appropriate model of programming is a developmental model, according to which retarded children and adults are considered capable of growth, learning and development. Each individual has the potential for some progress, no matter how severely impaired he might be.

From these basic principles and prior position statements by the Association, certain logical conclusions can be drawn regarding specific problems within any aspect of the service delivery system. The following discussions deal with identified problems related to nursing homes in a system of residential services. Positions of the Association are enunciated within three areas of responsibility: (1) accountability; (2) individual program planning; and (3) economic considerations. In addition, 11 questions are suggested as relevant to the selection of a specialized residential environment which meets the needs of the mentally retarded individual.

Those persons who are providing a place of residence for mentally retarded individuals are answerable to those who are receiving this service as well as those who are paying for the service. The issues of accountability become particularly crucial in residential services for mentally retarded persons. Without advocate monitoring of residential facilities and programs, deprivation of basic human rights is more likely to occur.

Accountability

ISSUE: LICENSING AND MONITORING

Nursing homes and ICFs are too frequently licensed and monitored by agencies and persons lacking necessary familiarity and expertise in the area of mental retardation. It has been further noted that people responsible for determining a facility's compliance with regulations are often placed in conflict-of-interest positions. The federal regulations for ICF/MRs have been loosely interpreted and, in some instances, ignored completely in important programmatic areas.

POSITION:

Surveyors of ICF/MR programs should be generalists in the field of mental retardation who are able to recognize the unique contributions of all disciplines. A predominance of surveyors from any one discipline may tend to emphasize a single model which is contrary to an interdisciplinary approach.

Furthermore, surveyors should be knowledgeable in the principles of appropriate contemporary programming, emphasizing developmental theory, the concept of normalization, client program coordination, individual program planning and evaluation, human and legal rights, relevant assessments and the utilization of generic services.

A comprehensive training program to familiarize surveyors with the ICF/MR regulations and the process of evaluation, along with an ongoing surveyor evaluation program, should be developed and required for all those currently employed, as well as future surveyors.

The state agency that certifies nursing home or intermediate care facilities should be separate from the agency that provides programs. Likewise, no surveyor should be employed by an agency that is eligible for or receives Medicaid funds. Ideally, the agency certifying compliance with ICF/MR regulations should be divorced from any form of political pressure.

Survey procedures should be evaluated periodically to ensure that the agencies being certified are, in fact, in compliance with the regulations. Survey reports should be made available to the public to ensure ongoing compliance as well as the implementation of recommendations to eliminate deficiencies.

ISSUE: PLACEMENT IN RESIDENTIAL FACILITIES

The availability of monies and the perception of a retarded person as having fewer needs than the average nursing home patient have encouraged some providers of nursing home services to compete for the mentally retarded client without regard for his or her developmental needs.

POSITION:

The placement of an individual in any particular residential setting must be a function of that individual's need at that point in time. To ensure that a mentally retarded person receives appropriate services at the right time, attention must be directed toward agency coordination within state and community service delivery systems. Each unit of the service delivery system must participate in an annual review of the effectiveness of the system with emphasis on the unmet, identified client needs within that system. Such review should involve an interagency review process, including volunteer advocates.

The units of a service delivery system should establish clearly defined procedures for case management and follow-along in order to assure that when a client moves from one agency to the next he is not lost in the shuffle. Such procedures will

indicate when one agency may terminate its follow-along responsibility and, at the same time, identify which agency will succeed it in primary case-management responsibility.

Within a given agency, there must be an identified locus of responsibility for implementation of the individual program plan. Likewise, within a given service delivery system there must be an identified locus of responsibility for the coordination process, with legal and procedural provisions for enforcement of individual agency responsibilities. The makeup of the service delivery system should be so well identified that voluntary agencies representing the consumers can monitor services to ensure that all units are actively involved with coordination of the system, particularly where changes need to be brought about.

ISSUE: FACILITY ISOLATION

While the Medicaid regulations do allow for utilization of generic community resources and for the integration of residents into community systems, the perceptions of nursing home administrators are often incompatible with the concept of community integration.

POSITION:

If nursing homes and ICFs are to be used to provide residential services to those who require programs of a medical and rehabilitative nature, the facility's management must be educated as to the value and desirability of using community resources to support the developmental requirements of mentally retarded individuals.

Nursing homes or ICF services used to provide residential services for retarded persons must be integrated into the comprehensive service delivery system of the community.

Individual Program Planning

Residential programs for mentally retarded persons must serve to enhance the total functional capacity of each individual within that program. A residential service must be capable of providing, or securing, preventive, restorative and habilitative processes designed to assure to each person the right and the opportunity to learn and to exercise his personal relevance as a citizen and as a member of his community. Programs must assure continuing opportunities for clients to be productive, to experience life, to receive and give affection, to make a social contribution and to have freedom of choice in the manner of using these rights

and opportunities. The individual program plan is the mechanism by which a facility designs its services to meet these developmental needs of its mentally retarded clients. Health care and protection may be among the means to achieve these goals but they are not the primary objectives of a residential service for mentally retarded individuals.

ISSUE: INDIVIDUAL ASSESSMENT

The underlying medical model of nursing home operation tends to focus primarily, if not exclusively, on medical evaluations without adequate assessment of an individual's learning needs or of the facility's ability to meet those needs.

POSITION:

Every resident must receive an interdisciplinary assessment which includes, but is not limited to, sensorimotor, communicative, social, affective and cognitive development in addition to a comprehensive assessment of health status and medical needs. Interested family members, guardians or advocates should be involved in the assessment process.

All providers of services for mentally retarded individuals should, at least annually, evaluate their program effectiveness in meeting the developmental needs of their clients. The evaluation process should also include an assessment of the relationships between various service agency activities as they relate to the service delivery system as a whole.

ISSUE: PROGRAM LIMITATIONS

Residents of nursing homes frequently spend their days sitting idly or lying in bed with only occasional medical treatments or crafts activities to fill their day.

Nursing homes or their programs are frequently not structured to provide the diverse services necessary for meeting the comprehensive learning needs of mentally retarded persons.

POSITION:

An individual program plan must be written by an interdisciplinary team and implemented by staff members who are adequately prepared to assure the success of program goals.

Program design and implementation must be based on a developmental model and meet applicable criteria as established by the AC/FMR accreditation standards.

The individual program plan must also describe conditions, activities or barriers which may interfere with achievement of both long-term and short-term objectives. Short and long-term objectives must include a sequential approach to moving people from a more dependent environment to the least restrictive environment for each person.

Nursing homes with limited staff and program resources must reach out to the community to obtain appropriate services for their clients. The role of other agencies, including generic agencies, capable of delivering the services required should be identified. A locus of responsibility must be established for utilizing and coordinating the services provided by different practitioners or agencies.

If a facility has as its major purpose the maintenance of life, it is not an appropriate residence for mentally retarded people not in need of this service.

Economic Considerations

Quality residential services for individuals who are mentally retarded require adequate public support systems. States are making continuous efforts to obtain federal funds in order to secure necessary financing for quality programming.

The established Federal Medicaid Program allows for a convenient funding system and provides greater support for skilled nursing care than for intermediate care facilities. Since federal support of group homes is more difficult to establish than for either level of nursing care, there is a continued temptation for state administrations to develop non-medical residential services under skilled or ICF nursing home systems even though the primary purpose of nursing homes is to provide health related programs.

ISSUE: INAPPROPRIATE PLACEMENT

Standards and regulations required for nursing homes strongly influence the environment and program opportunities. The need for the retarded person to have an environment which provides for the development of social and living skills commands low priority in the nursing home system. Nursing home programs are basically prepared to provide a service where the client's health status is of primary concern.

POSITION:

Program needs of retarded individuals must clearly require the services of skilled nursing care before placement in a nursing home facility is considered. The

alternatives and choices available for the retarded person must be adequate to allow for appropriate placement and movement, based on individual needs.

ISSUE: LOSS OF STATE DOLLARS

The development of a funding source for residential programs through the improper use of federal nursing home regulations may prove costly to the resident. Once a funding system is established, complying with nursing home regulations in order to assure continued funding will likely take priority over the developmental needs of the retarded person.

Federal financial assistance for state programs is provided to improve the quality of services available to the client. However, federal funding frequently replaces, rather than supplements, state and local funds, resulting in little or no improvement in services provided.

POSITION:

Program needs of retarded persons must continue to be adequately funded through state and local resources. Citizen action must be developed to establish legislation and regulations which will assure the maintenance of effort by the state funding system. A retarded individual must not be arbitrarily placed in a nursing home environment simply on the basis of economic considerations. Each individual must be provided an opportunity to live in the least restrictive environment suitable to meet his or her developmental needs. Adequate local, state and federal funding mechanisms must be developed to support normalized residential programs and to assure adequate choices among residential services.

APPENDIX

Some Questions Regarding the Selection of a Residential Service

The evolution of valid assessment techniques, by which the advocate organization can monitor residential placement decisions, involves careful questioning of individual factors in determining criteria for admission to a residential program.

In view of the complexities surrounding the decision to seek a residential placement outside of the natural home, consideration of the following questions should be of assistance in the selection and timing process:

MEDICAL NEEDS:

1. What are the specific medical problems which cannot be attended to by non-medical persons?
2. Are these problems chronic or acute?
3. Do these medical needs impact on the developmental program needs of the individual and if so, to what extent?

LEVEL OF HEALTH MAINTENANCE:

1. Is the individual continuously susceptible to acute medical problems?
2. Are certain environmental conditions conducive to the deterioration, maintenance or improvement of the person's health? Can appropriate conditions be provided in a non-medical facility?

DEVELOPMENTAL NEEDS:

1. Does the facility have available to it specialists to assess and program for the individual's continuing development?
2. Is the program dynamic and progressive with an orientation to the increasing development of the whole person and his/her individual skills, or is the program static and custodial with an exclusive orientation to the maintenance of life and related medical needs?

LEVEL OF INDEPENDENCE:

1. Is the individual capable of physical autonomy and if not, what are his/her physical disabilities and limitations?
2. What is the repertoire of life skills possessed by the individual?

3. Are existing limitations addressed in a developmental program plan?
4. What environmental features and staffing are necessary to enhance the person's level of independent functioning and are these readily available to the residential facility?

PROGRESSIVE DETERIORATION:

1. Is there conclusive medical evidence of a progressively deteriorating disease?
2. Is the disease process potentially reversible or subject to treatment?

AVAILABILITY OF COMMUNITY SERVICES:

1. Has the community been assessed to determine if it has the resources available to assist the family and the individual to maintain residence in his/her natural home?
2. Are such services available to be delivered in the home as well as in the community? If not, is appropriate transportation available to and from the community resources?
3. Are such service organizations adequately funded or is funding available to the individual through financial assistance programs?
4. Are such services available as long as necessary or only for emergency purposes?

FAMILY'S ABILITY:

1. Is there a person at home adequately motivated and capable of attending to the needs of the individual?
2. Are both parents physically capable of providing needed physical assistance to the individual or are assistive devices available for them to do so?
3. Are counseling services available for the family wishing to continue the individual's residence at home?
4. Are trained personnel available for evening or weekend family respite?

ALTERNATIVES:

1. Have all community services to support continued home residence been explored?

2. Has a full range of residential facilities been explored and are they linked one to another on a developmental continuum?
3. Does the community provide short-term respite services as an alternative to extended residential placement outside of the home?

PERSONAL CHOICE:

1. Has the individual and/or the family had an opportunity to review all available resources and to participate actively in the decision-making process?
2. Were choices presented on the basis of the individual's assessment and his/her individualized program plan compiled by an interdisciplinary team?

LEAST RESTRICTIVE ENVIRONMENT:

1. Does the residential facility provide an environment which is the "least restrictive" capable of meeting the individual's needs?
2. If the least restrictive environment is not available, are plans underway for the development of a full continuum of residential services to provide the individual with the least restrictive environment appropriate to the individual's needs at various points in his/her life?

FOLLOW-ALONG:

1. Does the residential facility provide follow-along services including periodic (at least annual) re-evaluation and program planning?
2. Does the residential facility coordinate services with other agencies and is it willing to transfer the individual to a more appropriate facility and environment as determined by the individual's medical and developmental needs?

Adopted by:
NARC Board of Directors
October 19, 1975

1975
NARC RESIDENTIAL SERVICES & FACILITIES SUBCOMMITTEE

Mrs. Eleanor Elkin, Chairman
Philadelphia, Pennsylvania

Mrs. Dolores Norley
West Palm Beach, Florida

Mr. F. Joe Barnett
Pocatello, Idaho

Mr. H. David Sokoloff
San Francisco, California

Mrs. Mary Lee Brookshire
Stone Mountain, Georgia

Mr. Joe Winters
Kansas City, Missouri

Mrs. Rita Charron
East Lansing, Michigan

Dr. Charles Seevers
Bristol, Indiana

Mrs. Patricia Clapp
Pittsburgh, Pennsylvania

Miss Evelyn Provitt
Lansing, Michigan

Frank J. Menolascino, M.D., Board Coordinator
for Program Services, Omaha, Nebraska

Gene Patterson, Program Services Consultant