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Achievements in Residential Services for Persons With Disabilities

TOWARD EXCELLENCE

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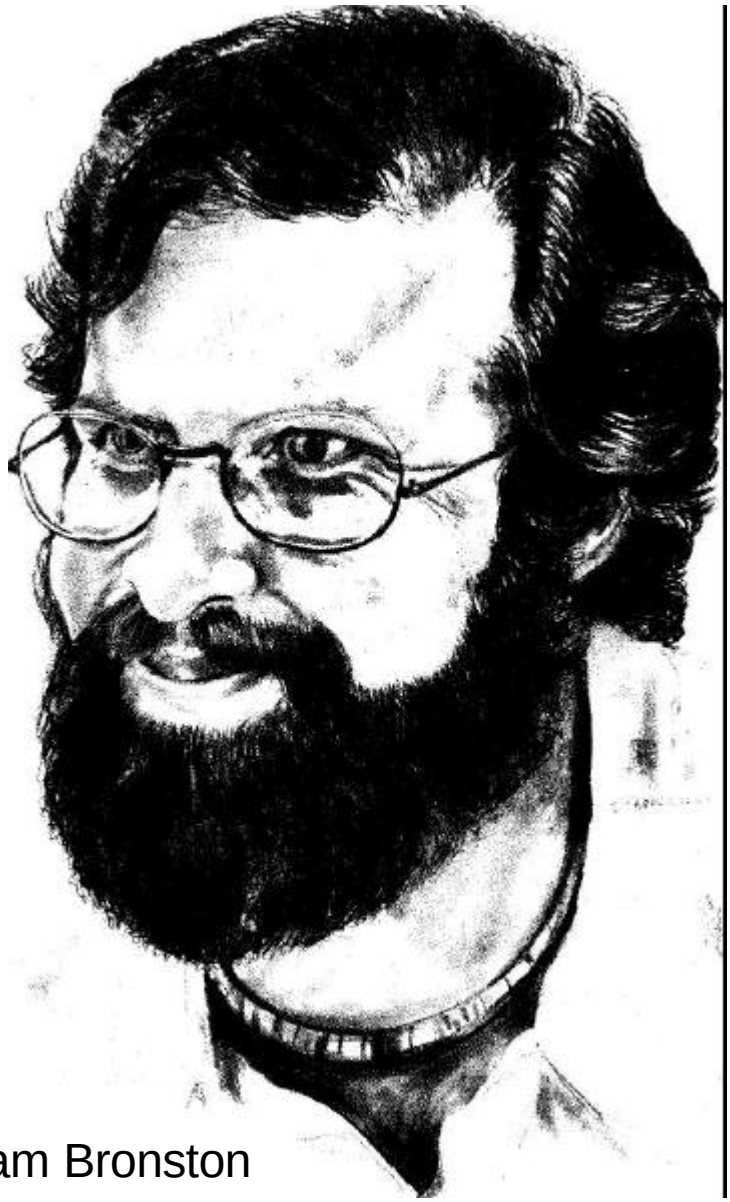
Baltimore

THE SHAPE OF A MARATHON



William Bronston

*there officially exists in California a philos-*ophy of services that is based deeply on values. It submits that i order to grow, each person deserves:

Love, honor, and freedom from stigma throughout life
Celebration of being special
A life-sharing family, home, and nurturing support
A community of concern and friendship
Economic security, health, and the full benefit of modern technol-
ogy with a varied continuum of services Freedom from the threat of injury due to pollution of food, a
water, and the earth on which we dwell The opportunity to grow, learn, choose, work, rest, play, be nour-
ished, to experience well-being Solitude when needed
Comfort and beauty in which to discover himself or herself

The power to improve his or her environment
Justice
The dignity of risk, joy, and growth of spirit
A valid social future

Such philosophy sums up many of the deepest held beliefs about quality of life. These beliefs are at the root of our current and emerging civil rights and human services laws and standards.

How we, as human beings, are perceived decides how we are treated in society. Our judicial system declared its stand to defend the virtue and inalienable right for life: a commitment to change and growth, respect for each person based on individual identity, equality of opportunity, access to resources, full social integration, the right to privacy, the ability to exercise a voice in social affairs, and self-determination. These rights are rooted in and interpreted from our constitutional guarantees. They have been translated over recent years and summed up in the principle of normalization in human service. This principle forms a bridge between ideas expressed in our ideal cultural values and their implementation in society's caregiving structures. Normalization in theory and operation offers a standard of minimum acceptability on which human services must be conceived, planned, provided, and judged.

Normalization advocates the use of *means* that are culturally normative in order to offer a person life conditions *at least as good* as those of the average citizen and, as much as possible, to enhance and support personal behaviors, appearance, experience, status, and reputation to the greatest degree possible, at any given time, for each individual according to his or her special developmental needs (1, 2).

Normalization insists upon accentuating the positive and eliminating the negative by doing everything possible to integrate people who have special needs into everyday lives so that they may enjoy all we value for ourselves.

Normalization dictates use of the least restrictive or drastic means to help people grow and change to avoid stifling personal liberty. This notion also applies to how we socially burden or enhance human beings with our labels, the use of technology, the location and appearances of the buildings and spaces where services are carried on, and the image and impact of the kinds and numbers of service workers employed. All these influence how

people served are seen and are decisive in shaping everyone's ex pectations, actions, and therefore the benefits or outcomes of set vice for individuals.

What is the best way to assist people in society to achieve and enjoy the fruits of that society? How do we assure not only that we do no harm, but that we uplift the persons we serve in the eye of their fellow citizens? How do we balance the clinical or educa-tional benefit of using methods that improve competence and performance with the cost in status and reputation of culturall stigmatizing measures? How do we protect the sense of person well-being, confidence, dignity, and pride of a person in an inter-dependent relation with services and staffs who do not, or will not identify with that person as a peer of equal worth? How do we rec-ognize the right to treatment and help that each person possess in our society, while eliminating ineffective programs that repre-sent deprivations of liberty and impose overly restrictive alterna-tives? How do we implement the responsibility as teachers are caregivers such that, in the words of John Donne, "No man is island, entire of itself; every man is a piece of the continent, a path of the main. . . any man's death diminishes me, because I am volved in mankind. . . "?

This anthology is already a history book, yet the experience and values addressed here are almost nonexistent in the literature of developmental services.

This summing up of the state of the art in the creation of life-style services paints a picture of what has happened in several places. It is up to us to garner the lessons of this search for excel-lence, and push forward to an even more civilized and humane future. Presented here is the tapestry of ideas and practice, woven together, one giving impetus to another in a progressive act of provement.

Clearly, Nebraska with its ENCOR experience became the cor-nerstone for the fundamental challenge to North American human services. The uncompromising commitment to an ideology of vice, developed in great detail as the principle of normalization made almost everything that preceded it in the field obsolete There is no way to fully measure the impact of such a contrac-tion. It exploded the possible in the field through an idea, he leaders, and a concrete model. The idea, like dandelion seed car on the wind, spread to consumers, planners, teachers, service pro-viders, advocates, and researchers alike. If we do our job well may at least derive the following service benefits or actions:

Institution placements prevented
Persons returned from institutions
Emotional breakdowns prevented
Family breakup averted
Loneliness dispelled
Health preserved or restored
Services or social participation enhanced
Proper treatment provided
Persons habilitated
Dollars saved
Personnel needs reduced
Justice rendered or preserved

We are still in the first mile, a mere decade, into a marathon that will stretch on and on toward the excellence of attainment and fulfillment. We can draw ourselves forward together into this demanding run. Tangible rewards of the race are reaped while we labor with both love and science to transform our society. Intangible intimate rewards of the effort are realized as personal records that are continually broken every minute of the way toward our common destiny.

It is in this spirit that this material is set forth. It is intended to create understanding of the continuum of appropriate help and living arrangement services needed for people with special developmental needs. It is meant to be a small commitment to common humanity and respect for every human being.

REFERENCES

1. Wolfensberger, W. 1972. The Principle of Normalization in Human Services. National Institute on Mental Retardation, Toronto.
2. *Way to Go.* 1978. University Park Press, Baltimore.

MATTERS OF DESIGN

William Bronston

THE SUBSTANCE OF THE LIVING ARRANGEMENT ISSUE

the chapters ahead, there are sequences of basic ideas, principles, and models that summarize the key con-temporary living arrangement issues. The following outline some key checklists that provide a reference and priority : most important issues. Recognizing the power of environment in our culture to act as a medium of status and identity, we must take stock of the attitudes and philosophies that underlie the design of a residence. We must ask and honestly answer:

1. What is the meaning embodied in or conveyed by the environ-
   ment?
2. For whose convenience was the environment designed
3. What role expectancies does the environmental design upon the clients-users?

We rely almost entirely on the assumption that people with special needs do not have equality or common value as pec

once alienated from their families, require *paid for* care. Our system is based on buying help—professional services, shift staff. Buying help is an industry that we manipulate—parent and public official alike. Our cultural institutions have not, as many European and non-Anglo societies have, embraced our vulnerable members as part of the family of man, deserving love, comfort, dignity, and intimate relations. Thus, we labor to create a situation whose foundation is always dangerously weak and subject to the winds of cruelty and inhumanity that have blown strongly in our century.

Stereotypes predominate. We must find ways to eliminate popular beliefs, which are based upon what the public has learned from the past about disability. We must teach our citizens to believe in our capacity to emancipate people with disabilities through new environments and magnificent scientific achievements.

Having been pushed to the margins of society, looking and acting very differently, congregated, and subjected to benign hopelessness, our constituency has been devastated in the eyes of most people. We seem to be discovering truths about life and growth that are old hat for valued sectors of society, but are breakthroughs that must be fought for when people are labeled "retarded" or "disabled" in one form or another.

This "discovery" of common sense, this celebration of the obvious in the design of decent living should evoke considerable embarrassment and even humble apology from the professions and bureaucracies that have teamed up to cling to institutions and service segregation.

TRADITIONAL LIVING ARRANGEMENTS NETWORK

The traditional continuum of living arrangements has emphasized a network of facilities that includes:

Large state hospitals	
Skilled nursing facilities	
Intermediate care facilities	
Residential school facilities	
Board and care facilities	Ranging from small to large
Group home facilities	

Semi-independent living situations	In one's own home, an apartment, a foster care situation, or a small family living group
Independent living situations	

Underlying this network, improperly identified as a continuum, has been the assumption that, the more complex and severe the individual's need and areas of dependency, the more likely it is that the person will be served in a large, segregated pro-gram. On the other hand, the assumption goes, the more compe-tent and able the individual, the more likely it is that he or she will best live in a small home. A related assumption is that service (care and supervision) in large facilities where individuals are con-gregated (state hospitals, skilled nursing facilities) will be pro-vided by staff who live away from the facility and work on a shift basis within it. Conversely, similar services in small, home-like facilities will be provided by "live-in" staff. Experience shows that these rigidly held assumptions are clearly outmoded. A need exists to reform this traditional outlook, whose continued exis-tence is challenged by our evolving social values and technology. When existing living arrangements are assessed against 1 principles and standards of normalization and civil rights guaran-tees, the following problems emerge:

1. Residential services are inflexible, built as they are on ponder-ous laws and regulations. Such services are *not* designed to assure movement through the system in keeping with an dividual's growth. There is no *planned and assured option physical movement* from program to program, or facility to facility, or for programmatic change within any given setting in accordance with individual needs, much less to provide choices and transition.
2. There has not been a commitment to systematic program-ming in every living arrangement that supports and enhances individual growth and development and is intentional and versal.
3. There has not been a commitment to systematic staff develop-ment that would assure the availability of sufficient knowl-edgeable and competent service workers (including can ers) fully grounded in program philosophy and progressively advancing toward career objectives with state sanction.

4. Program and facilities have not been designed according to a clear-cut continuum of less restrictive alternatives to individ ual liberty and autonomy.
5. Living arrangements have not been designed to be appropri ate to the chronological age of the individual. Too frequently there has been a mixing of individuals of widely disparate ages, outside of natural, foster, or adoptive family situations. This has led to poor personal images and low program expec tations for both children and adults alike.
6. Individuals with different categorical labels and types of dis ability have been mixed in the same facility. This has resulted in a devalued image and program hodgepodge for the individ uals involved, instead of providing them with opportunities and models for social integration with typical peers.
7. Current individual living arrangements have been maintained in spite of the fact that they are not the least restrictive alter native and where, as a result, the developmental needs of per sons have not been met.
8. In the overwhelming majority of states, nowhere is there a complete continuum of living arrangements. Many individ uals are placed according to what is locally available or in a more appropriate program far from home communities, rather than according to what is needed and desirable.
9. There is no statutory mandate for direct provision of living ar rangements that meshes public and private resources appro priately, and that acts to eliminate the reality of excessive competition, duplication, and fragmentation.

THE DESIGN FOR A TRANSITIONAL LIVING ARRANGEMENTS CONTINUUM

Because of the shortcomings identified of the traditional network of living arrangements, we can propose to remedy the situation with the design shown in Figure 1, a design that reduces pseudo-diversity to the most basic elements. Such a model acknowledges what exists and the need to strengthen and reinforce the preferred parts while providing disincentives for the unacceptable and un-desirable components.

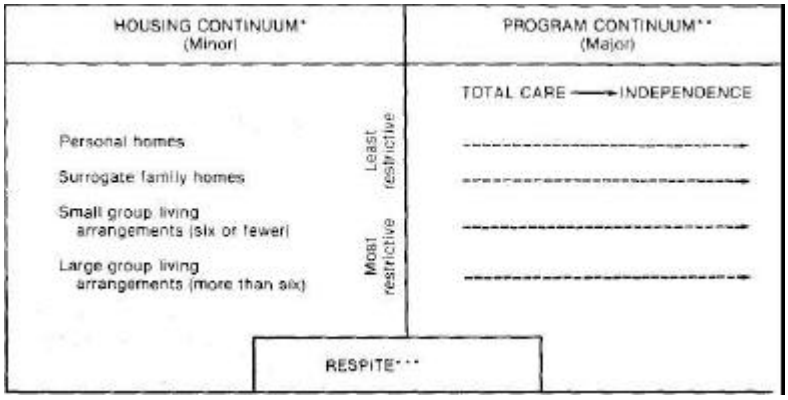


Figure 1. A transitional living arrangement continuum. *Includes facilities operating under both public and private auspices and those that are not for profit as well as those that are proprietary. **Clients in the housing (minor) continuum will be situated in the program (major) continuum according to their individual special developmental needs and program plan. ***Cuts across the living arrangements continuum, i.e., has both program and housing components.

RATIONALE FOR THE DESIGN OF THE COMPREHENSIVE LIVING ARRANGEMENTS CONTINUUM

The housing continuum contains within it a full range of compo-nents from the ideal (least restrictive-most typical) to the least acceptable alternative to that ideal (most restrictive-least typi-cal). It is assumed that any given individual with development services needs will come into the housing continuum at any p and, barring unforeseen circumstances, move along it progres-sively toward the ideal.

The program continuum likewise contains within it a range of components from its beginning point—total care—to its goal— independence. It is assumed that any given individual will come into the continuum at any point and, again barring unfore-seen circumstances, move progressively along it toward max-imum autonomy and well-being.

Although the major and minor continua may be considered independently, they are interrelated components of the compre-hensive living arrangements continuum. In this comprehensive continuum model, both program and housing needs must be ad-dressed systematically and simultaneously.

Available experience in the nation establishes that there are all kinds of people with all kinds of problems in all kinds of settings getting all kinds of services. Thus, at any point on the program continuum-and, conversely, at given points in the program continuum—individuals can make their home at any point on the housing continuum.

Beyond these basics, a person's age is one of the most sensitive considerations that must be superimposed upon the major and minor continua. Separation by age, although basic to the respectful acknowledgment of a person and means by which to assure proper attitudes and program design, cannot be dogmatically exercised. A few considerations are central.

A person usually lives with parents or parent surrogates during childhood. Upon reaching the age of independence, individuals typically seek their own domicile. It is unusual in our culture for a person to return to or stay in his or her parents' home except for respite periods of transition, sanctuary, or the like.

Furthermore, it is only in the natural family that a range of age from infancy through adulthood is typical. Adults or teenagers near adulthood must be accorded an age status and culturally enhancing environment that does not further burden the image of "eternal child."

In relation to the issue of appropriate and enhancing living arrangements for children, if the maxim "support, do not supplant the family" cannot be achieved, then out-of-home placement for children must emphasize the most individualized of all relations. The younger the person, the more in need is that person of a single caregiver and continuity of care. Single-person living arrangements for children are preferred, coupled with social integration with typical peers in all activities.

Some examples of desirable service universals that are particularly relevant to living arrangements include:

1. Ready access
2. Aesthetics of facility
3. Physically comfortable facility
4. Age-appropriate facilities and service approaches
5. Positive value image of service and clients
6. Intense programming
7. Individualization
8. Respectful, warm social interactions

9. Social integration
10. Meaningful participation of consumers and public
11. Self-renewal orientation
12. Receptivity to research
13. Ties to academia

The following considerations should help us to rank order ternatives on a *continuum:*

1. Support, not supplant, the natural home.
2. Use foster placement or family-like settings, especially children.
3. If you must use a non-family setting, lease, don't buy.
4. Buy an existing structure, don't build.
5. Build a typical home, not special.
6. Build a special structure within the community, not isolated.

There seems to be at least four major arguments favoring small residential settings: 1) the group and residence do not at tract undue attention by being larger than a large family; 2) the larger a grouping of perceived deviant individuals, the less likely it is that the neighborhood and its resources will absorb them; 3) large groups become self-sufficient, orient inward, and resist out-ward integration; and 4) when groups are larger than six or eight, house parents or resident advisors can no longer properly relate to individual group members and structure the group.

The setting in which persons are served should absolutely not be equated with the degree or complexity of their disability. Tradi-tionally, our field has established the formula of placing the most disabled person in the most medical/segregated/congregate set-ting and considering normative dwellings only for independent or semi-independent living. In fact, the key and decisive variable is the competence and quality of the caregiver. That is to say, pro-gram is what counts. Thus, almost without exception, apartment dwellings could suffice for all our service needs, except where gross acute medical/hospital services were needed to stabilize a person for short-term duration. Benefits of apartment living are:

1. Flexibility in programming
2. Normalization for tenants
3. Integration of tenants into the community
4. Improvement of the cost-benefit ratio
5. Extension of the continuum of residential services

6. Quick start-up of program
7. Elimination of most or all zoning and building code barriers

Once we have exhausted less restrictive alternatives and are definitely faced with an out-of-home placement, 10 considerations must be simultaneously addressed. Our aim is to make possible a quality of life that matches as closely as possible family familiarity and security. Community living arrangements must be:

1. Normalizing and adaptive Dispersed across and within
2. population centers Socially and physically integrated in the
3. community Age appropriate in setting design, decor,
4. structures, and rhythms
   Separate from other daily living functions, such as school,
5. work, play Small (size of group)
   The least restrictive alternative setting and structure
6. Designed for high diversity of models (specialization) In a
7. continuum with other residential and nonresidential services
8. Supportive of staff-tenant relationships
9. The matter of staff-tenant relations seems the most delicate.
   The distance created by a professional (paid) caregiver as
10. opposed to a person who seeks the caregiver relation based

first on spontaneous friendship or love requires constant attention. The staff is a vital component in maximizing culturally typical relations, or "life sharing." Regardless, all living arrangements should maximize:

1. Diminishing rather than accentuating distinctions between staff and clients
2. Staff and clients sharing space, toilets, meals, real recrea tion, fun, vacations, joy, song, suffering, worship, etc.
3. Living with (not just close to) clients
4. Maximizing peer modeling
5. Enhancing direct contact by volunteers.

At a more system-wide level, such comprehensive and rational living arrangements models must be planned and generated by significant administrative commitment and structures. Such requirements include at least:

1. Community living branch in state government
2. Local community living arrangements provider agency
3. Performance agreements between local agencies and state government
4. Use of existing geopolitical boundaries for regional service areas
5. Mandatory and continuous personnel development an< training
6. Evaluation and data collection capacity
7. Quarterly advance funding for start-up
8. Quality review mechanism and standards
9. Advocacy and monitoring safeguards
10. Development of normalized zoning and building codes and licensing rules (anti-ghettoization)

At the local/regional level of service delivery, a publicly funded and administered agency (quasi-public or public authority or joint powers board) is essential if state services (institutions) are to be decentralized and transformed. Only in this way can assurances be made to free parent organizations from clinging to archaic property and buildings and ultimately to become free of the role of provider of last resort.

This local/regional public agency must be responsible to:

1. Administer programs
2. Provide residential planning and services for all persons from the service area, including persons from the locale presently living in state institutions
3. Mobilize public support for residential services
4. Provide or purchase needed services to include: family subsidy, in-home support, foster placements, respite, crisis assistance, subsidized adoptive programs, independent living, semi-independent living, group living for six or fewer, specialized living programs
5. Develop local resources to support residents in nondomiciliary life needs

FINALE: THE STARTING PLACE

Normal living settings represent only the structural hub if services are to be relevant, personal, and developmental. A number of satellite forces and conditions must keep the constellation in dynamic balance, depicted in Figure 2.

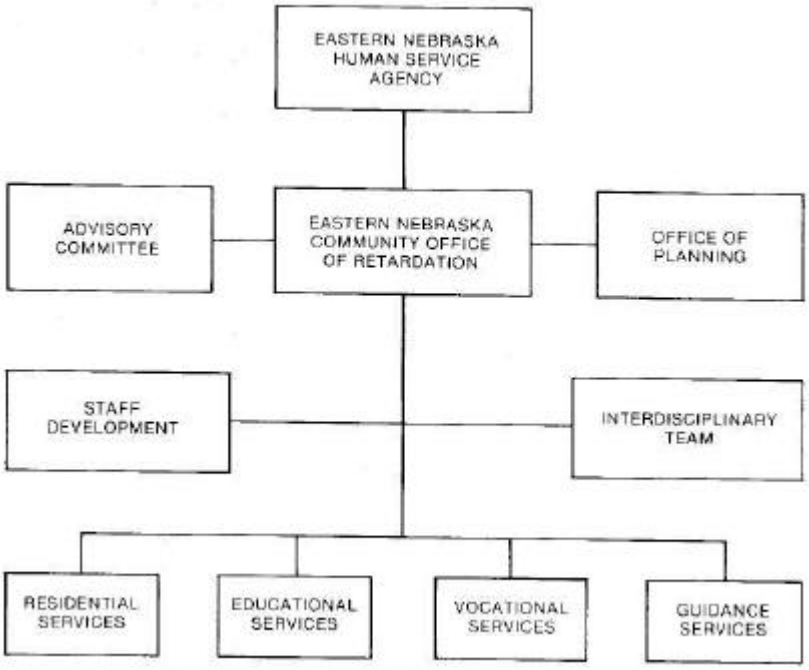
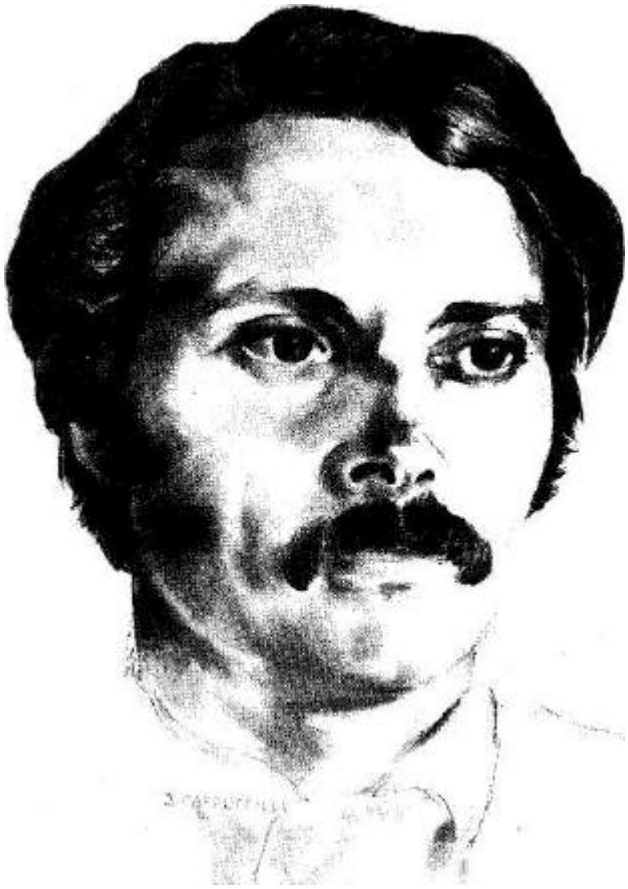


Figure 2. Constellation of essential service forces in a full continuum.

Institutions, however archaic, remain. As long as institutional models exist, every realistic effort must be made to upgrade their services and enhance the quality of life for those persons who reside and work there. Nevertheless, commitment must be made to stop all proposed institutional and residential construction, to eliminate plans for new traditional institutions, and to effect orderly deinstitutionalization with strict safeguards, advocacy, and monitoring.

In summary, four levels of action are called for: 1) increase community services and decrease need for residential places; 2) replace large institutions with small, dispersed, specialized residences and apartments; 3) return institution residents to society, community, or family; and 4) improve institutions as long as needed. These checklists but scratch the surface, yet the scope and possibilities of the situation are suggested. As each contributor to this volume describes his or her work, these criteria will correlate and take on concrete implications and interpretations.

THE MACOMB-OAKLAND REGIONAL CENTER



Gerald Provencal

this chapter focuses on four areas: 1) the agency I work for, 2) two of our residential alternatives, which I believe are unique, at least in some aspects of their management and staff training, 3) the training strategy that is an intrinsic part of my agency's programs, and 4) the strengths and weaknesses of our training per se, including some trade secrets on how our train-ing program works.

MACOMB-OAKLAND REGIONAL CENTER

The Macomb-Oakland Regional Center is one part of the state sys-tem of mental retardation services in Michigan. Macomb and Oak-land counties are located just north of the Detroit metropolitan area. Their combined areas include some 1,300 square miles, with a total population of just under 2 million. We have high living standards in some spots and some strong poverty pockets. We have very educated people and we have people who are not very well educated. It is representative of most suburban areas.

Macomb-Oakland Regional Center is a state institution. By statute, we are responsible for every "mentally retarded" citizen who might need institutional services in our two-county area. This means that we have to admit people, discharge people, and maintain active legal responsibility for the care, training, and habilitation of over 800 clients in our two counties as well as a potential client caseload of over 35,000 individuals.

A brief history of our agency should give the reader a better perspective from which to judge the programs that I describe later in this chapter. The Macomb-Oakland Regional Center really began in 1971, in the minds of some parents and legislators. At that time, if you were "mentally retarded" and lived in Macomb or Oakland counties, you either stayed at home or went off to a state institution that was over 50 miles away. It was seen as a very positive step, in 1971, to build an institution that was both close to home and more individually accommodating than institutions of the past. Parents and legislators came together and talked with architectural firms and program consultants about what a good institution should look like. They discussed architectural design, program elements that should be in place, and the attributes of staff that should be recruited in order to build a "good institution." An architectural firm was hired to prepare the plans and the parents, legislators, and professionals in the area were very pleased with the 750-bed facility that was designed.

The Macomb-Oakland Regional Center was established by state statute in 1972. The people hired at that time, including myself, thought it a positive thing that we were going to have a better institution, but that it would be an even better thing if we didn't have any institution at all. We assembled a like-minded, core group of people who strongly believed that the best institution is not necessarily the best solution, and set out to make the institution obsolete before it opened.

We were in a very fortunate position at that time in that we were recognized as having a responsibility for citizens from our area who had previously gone to state institutions. As a result, we could go to any of the out-of-state institutions and ask for names and descriptive information of all residents who were native to our two-county area. This was very important to our placement efforts because our staff began to become familiar with, and identify with, individuals whom we felt could lead fuller lives in the larger community.

The institution staffs we worked with were skeptical about our objectives and they really didn't expect that we would move many people to the larger community. They didn't anticipate that we would be able to affect their overall operation greatly, and so they cooperated, without faith perhaps, but they cooperated.

The results of our efforts are noteworthy. There were l,400 people from our catchment area living in state institutions in 1972. Today there are 600. We have moved 800 out! Over the last 5V2 years, we have had 18 admissions to institutions, and over the last 2 years, we have had two. The institution that was originally planned for 750 people has 90 beds. During the period from 1972 until today, we have developed a wide range of housing alternatives to the institutions. We didn't quite meet our goal of making the "good institution" literally obsolete, but we are now sure that we never needed it. Although they don't all believe it, most parents and legislators also now realize that we didn't have to have the institution.

COMMUNITY-BASED RESIDENTIAL ALTERNATIVES

Many times retarded citizens are placed in institutions almost by dafault. The consensus of opinion frequently is that, "The institu-tion is the only place we can turn to." This rationale stems in part from the perception that if the natural parents of a "mentally retarded" citizen cannot maintain him or her at home, then no one else can either. If there are no relatives who can take on the responsibility from the parents, then the institution is sought as the last, if not the only, alternative.

Over the years, the absence of alternatives to the natural home and the institution has become so predictable that parents and professionals have stopped looking for them. With this search being either abbreviated or nonexistent, the institution takes on greater value as the alternative of choice; it appears to be the best alternative, even a good or desirable one. Institutional admission then completes a circle that owes much of its origin to self-fulfill-ing prophecy.

At Macomb-Oakland, we made a different use of the self-ful-filling prophecy. We discarded the notion that the institution ever had to be the " only thing left to turn to." We set out on a course to provide alternatives to parents of "mentally retarded" citizens who were unable to care for their sons and daughters at home; we

essentially acted on the premise that, if we worked diligently at establishing preferable alternatives to the institution, we could eliminate all default admissions and move people to the larger community who were already inappropriately placed within institutions. This premise is rather simplistic, but we were convinced that the nature of the problem had been given too much credit for complexity.

Group Homes

We have basically used two residential models in our efforts to make the institution unnecessary—the group home and the community training home. Our 30 group homes, none of which existed when we opened in 1972, range in size from 4 to 12 clients, the average being 7. We have about 250 people living in group homes. The average cost of the homes is approximately $35 per day per resident, made up by Supplemental Security Income payments, state monies, and Title XX match money. All of the group homes that we have are operated by nonprofit corporations. We run none of them directly. We contract for services. None of the 15 nonprofit corporations that now run our homes existed before fall, 1972. We began by working with people we thought might be interested in running group homes. We showed them how to incorporate and how to set up the kinds of alternative structures that we wanted.

The administrators or managers, who are primarily responsible for the homes, are usually college graduates with a cause. They generally are not too much concerned with making money; they want to do something for people.

The responsibilities of group home administrators are several. In addition to managing their home, their budget, and routine responsibilities for food, transportation, and so forth, they must also attend training sessions on a monthly basis and staff meetings on all their clients' individualized program plans on a quarterly basis.

Some of our homes are staffed by couples, but most are staffed by single people without live-in personnel. The average wage of direct care personnel is about $3.25 an hour. All the residents in our homes go to public school programs or to some other major community activity during the day. Habilitation programs also occur within the homes. The staffs that operate the homes are recruited by the people we contract with, in cooperation with us.

We do reserve a kind of veto power. If we know an individual is being hired and we don't think he or she has the proper qualifications, we insist that another person be selected. We have also demanded that some staff members be fired for a variety of reasons. Most of the staff members that are hired for group homes are college students.

Direct care staffs are recruited in several ways. One of the best has been going to colleges, universities, and community colleges, and talking to classes of students who are enrolled in human services curricula. Holding 3-day seminars has also been very helpful. We discuss the needs of "handicapped" people, talk about how human services have evolved, and discuss career opportuni-ties for people interested in the field. These seminars have proved very effective in stimulating people to ask, "I might be interested in working in some capacity; could I sit down and talk about it fur-ther?"

The staff members living or working in our group homes are responsible for typical things: room, board, and supervision. They also have responsibility for some in-house programming. Every client living in one of our group homes receives in-house program ming 5 days a week, which complements whatever is going on in their major activity outside of the home. For example, someone in a school program might receive speech and language instruction and also receive related instruction at home. In this example, the speech teacher would meet with group home staff and discuss ways of carrying the speech program over into the home.

Community Training Homes

Our second major option to institutionalization is what we call the "community training home." The community training home concept is really an embellishment on the old foster home model Foster parents are well known to human services. Usually, they are people who want to do something good for somebody. Tradi-tionally, potential foster parents seek out an agency that has a clientele that can use their help. In other words, the foster par-ents initiate the relationship and the agency plays an almost passive selection role. We have taken a much different approach to the recruitment of foster parents and to the kinds of contribu-tions they offer. We have a very aggressive recruitment program. We use classified advertisements, posters, and speaking engage-ments throughout our two-county area. We talk to natural

parents, to existing foster parents, and to potential adoptive parents in hopes of generating interest in our community training program. We try to sell them on the challenges of living and working with a person who has special needs.

At the present time, we have 145 community training homes. The sizes of the homes range from one to three clients. The number is determined by the physical size of the house and by the management capability of the foster family. The cost of community training homes is about $25 a day per client, with the costs paid from Supplemental Security Income, state monies, and Title XX funds. About 95% of all the people living in our community training homes are children. Generally speaking, the group home program serves adults and the community training home program serves children; however, we are individualized in our approach to this so there are some variations. About 60% of the people living in group homes and community training homes have severe to profound mental retardation, and about 70% of these have serious secondary handicaps that, in the past, would have excluded them from community living.

We contract with all community training home foster parents and group home administrators by a written agreement that clarifies mutual expectations. Service providers must agree to supply room, board, supervision, and in-house programming 2 hours a day. Further responsibilities of the community training home operator are attendance at monthly training meetings, completion of monthly reports, meeting with each client's social worker on a monthly basis, and attendance at quarterly staff meetings. They must also satisfy things that are part of routine community life like taking people to doctor appointments, on shopping trips, and so forth.

The qualifications for operating a community training home are based upon both objective and interpretive criteria. The objective standards are building requirements, such as 90 square feet of bedroom space for each individual in the home, and placement standards, such as a maximum of three clients in the same home and a total maximum of seven people per home, including foster children and the members of the natural family.

The interpretive kinds of qualifications are probably the most important and the most difficult to evaluate. We talk in depth to potential candidates about expectations. We want to know just what would be anticipated of a new member of their household.

Would there be high expectations or would the new resident be perceived as being too helpless for it to matter? Does the candidate really want to make the client a part of the family or plan to treat the client in a passive way? We want to know what kinds of disciplinary methods are used in the home. We want to see if spanking or abusive language is used. We think that it is important whether or not potential foster parents are consistent in handling their own children and their own affairs. We are interested in whether or not the family thinks that the client coming into their home can make a contribution to the entire dynamic of the household or if he or she will just be an observer. We want to make certain that they see the person with special needs as a part of the family, and as an active participant within it. We seek candidates who view our client as somebody they want to accept fully and who are not interested primarily either in money or in working their way into heaven.

With regard to staff recruitment, the group home program is self-sustaining. Once we begin to do business with vendors, they take on the task of recruitment. They attract college students through informational meetings as described, advertise in the classified section of newspapers, follow up on interest shown by institutional staff looking for new challenges, and essentially take advantage of all known methods of stimulating interest in their programs among potential employees.

On the other hand, we are exclusively responsible for the recruitment of all foster parents for community training homes. We make use of several techniques. Some of the most successful are classified advertisements in local papers, adoption agency referrals and solicitations, public service announcements on both radio and television, and bulletins and posters distributed to schools libraries, and community centers. We have had success in follow-ing through on the referrals of other foster parents, and even natural parents. As a result of these initiatives, we receive be-tween 30 and 50 inquiries each month. Of these 30-50, only 1 or 2 eventually become foster parents. There are a vast number of reasons for applicants failing to complete the process required for foster parenting. Often, we feel people have not applied for the right reasons; they could not and will not be as considerate as they should be, or the time demands of being a service provider are too great. Others are not willing to complete our reports, to attend staff meetings, and so on. We want to have a program that pro-

vides an alternative for people that is far superior to an institution. To achieve this, we must place high expectations and high demands on the people who operate our community training homes. We strive to attract a large group of applicants so that we can be highly particular when selecting foster parents.

TRAINING RESIDENTIAL SERVICES PERSONNEL

Training Responsibilities

Our experience at Macomb-Oakland Regional Center has been instructive regarding the ways training can fit into the overall deinstitutionalization process. In 1972, many staff members and I felt that one way to get alternatives to institutions off the ground was to do a better job at recruiting and training staff and making better use of the existing foster home and group home concepts. It had been my experience that most foster parents approach the agency. Agencies do not approach them. The same is true for group home administrators. It also has been my experience that many of the best potential foster parents and group administrators are never even aware that such programs exist, or if they are aware, they perceive them as being ventures that only the elderly, very kind of heart, extremely patient, or other very exceptional people are interested in doing. We wanted to change this perception and we wanted to take advantage of the skills of people who could offer much but were unlikely to make the first contact. So we mounted an aggressive recruitment and training campaign aimed at this population. The results have been very worthwhile. We now have several hundred foster parents, adoptive parents, natural parents, and group home staffs living and working with highly difficult clients in the sense that most of them function at levels of severe to profound retardation and have significant secondary handicaps. We have been able to return these clients to home communities because we have selected the right people to receive them and we have taken very seriously our responsibility to ready the receivers. We select foster parents and group home personnel who are not only well qualified and interested in working with people who have special needs, but who are also committed to learning themselves. In this regard, we have found that the desire to *increase* knowledge of theories, trends, and techniques is a far better indicator of foster parent effec-

tiveness than years as a parent, educational degree, or years of background in the field. The importance of receptivity to new knowledge and directions from the agency cannot be oversold as a critical factor in community placement success. As a matter of fact, our experience has led us to believe that if we carefully select and prepare the people who will be receiving the person leaving the institution, virtually anyone can move to the community at large. This belief has led us to place tremendous efforts in training foster parents and group home personnel.

In relation to the points on selection and preparation, it has also been our experience that there is no prerequisite skill or ability that a client must acquire to ensure adequate placement adjustment. There is more than a bit of irony in this discovery- many dedicated professionals are still looking for predictive char-acteristics for community placement success within the personal-ity makeup or adaptive behavior profile of their clients. Many dedicated professionals are still trying to sort out the high risk people from the low risk people. Unfortunately, they are charac-terizing people rather than situations as risky. This notion has to change.

Institutions spend a great deal of time training attendants. One must have approximately 240 hours of inservice training on a variety of topics to work directly with the "retarded" who live in Michigan institutions, for example. Yet we all know that the wards serving institutionalized clients are understaffed and that attendants hardly ever have a chance to use the skills they learn within inservice classes. Relatively little money has been appro-priated, or imagination spent, on the other hand, on training peo-pie who are taking clients out of institutions. It's no wonder that clients are returning to institutions from the community.

We can develop all the residential alternatives we want, but if people keep bouncing back into institutions because the folks out there are not ready for them, we haven't done very much. The Na-tional Association of Superintendents of Public Residential Facil-ities regularly publishes statistics on where institutions are go-ing. Their data show that over 50% of people returning to institu-tions after trying to make it in the community return because they "fail to adjust." Nowhere is there any mention that they have been let down by an unambitious social worker or by an untrained foster parent who "failed to adjust." We in the field have a respon-sibility to provide environments wherein individual clients can ad-just. Clients have no obligation to adjust; we have an obligation to assure adjustment. I cannot overstress this point; it's too critical.

Curriculum Content

We decided that training was going to be an elementary part of our program. We didn't have any educators on the staff, nor did we have any members who really even knew much about training. We just had people who felt that it was important to train foster parents and group home personnel. So we assembled a large group of people who were knowledgeable about education. We found them by writing letters explaining our interests to community colleges, universities, University Affiliated Facilities, mental health departments, and departments of social services. We asked representatives from these agencies to meet with us to help identify a training strategy. Thirty people were interested enough to attend our meeting. Everybody liked the idea, but no one wanted to consider funding. Everybody endorsed the need, but nobody wanted to write the curriculum. Everybody thought it was a terrific idea, the greatest since sliced bread, but no one wanted to do the work. Nobody wanted to go to night meetings. Nobody wanted to send out brochures, and nobody wanted to help assemble the topics for potential training objectives. And so we saw another reason why no one is ever trained. Nobody wanted to do it because it wasn't anybody's job.

Eventually, two other people and I decided to put our efforts where our mouths were and prepare a curric ulum. We didn't proceed in any terribly scholarly fashion to find out what topics should be included in the curriculum. Instead, we sent out a well-thought-out questionnaire to all the foster parents in our community to see what they thought should be included. We asked them just two questions: what personal skills would make your job easier and what personal skills would make life better for the person living in your home? That's all, two things. Not 100 questions, not 16 questions, we didn't do a factor analysis, we just asked two questions. What would make your job better for you and what would make it better for the client you serve?

We received an extensive list of items which we proceeded to melt down to 50 potential topic areas (see Table 1). The topics included the role of group homes, first aid procedures, seizure information, the use of volunteers, insurance, discharge policies, advocacy, and toilet training. We took the 50 topics and divided them into two categories: mandatory core topics that we determined everyone must be exposed to, and an elective group of topics that we felt were important but not as fundamentally so as the first group. The core topics include orientations on: 1) mental

Table 1. Possible training and educational topics

? Role of Group Home
? Assisting Services
? Individual Programming
? Legal Considerations/Liability
? Orientation to Mental Retardataion
? First Aid
D Parent Involvement D Menus/Diet/Nutrition
? Sexuality
? Neighborhood Relations
? Record Keeping/Files
? Home Models
? Labeling
? Advance Administration
? Fire/Safety/Health
? Human Rights/Resident Rights
? Attitudes
? Educational/Vocational Programs
? Budgeting
? Gaming—Handling Situations and Behaviors
? Medications
? Seizures
? Academic Development
D Normalization
D Staff Roles/Job Descriptions
? Labor Laws
? Use of Volunteers
? Insurance
? Group Sessions for Residents
? Birth Control/Sterilization/ Abortion
? Leisure Time/Recreation Programs
? Marriage Considerations
? Discharge Policies
? License Regulations/ Standards
D Assessment Planning
? Speech
D Physical Therapy
? Sign Language
? Normal Child Development
? Emergency Procedures

? Dental Care
? Principles of Learning
? Changing Behavior
? Toilet Training
D Special Education
? Advocacy
? Special Adaptive Equipment
? Integration into Community Resources
? Group Home Evaluations
? Food Preparation/Ordering
? Other

retardation, 2) maintaining healthy environments, 3) fire and safety standards and procedures, 4) administrative responsibilities, 5) elements to be considered in programming, and 6) normalization. These topics seemed to encompass the fundamental understandings we expected! from foster parents and group home operators. They also were the topics most frequently mentioned as either being important to the home provider or the client in our survey.

To prepare participants, we send workbooks to everyone in advance of classes. They include the six topic outlines, an introduction to each session, a statement regarding why it is important, specific learning objectives for participants, a list of presenters and their credentials, a comment on what can be expected from them, references, and 10 discussion stimulants for each topic. Participants are also given information on when and where training will be held, when coffee will be served, when the breaks will occur, and so forth. We wanted to get rid of meeting in church basements, institution cafeterias, or inservice rooms. We specifically sought out community colleges as sites because we thought their atmosphere would be beneficial. The community colleges wouldn't help us write the curriculum, but they would let us use their classrooms. This collegiate setting lent a new air of legitimacy and learning to our training sessions. We wanted our training to be powerful, to be respected, to concentrate on subjects recognized as crucial to human services, to have very important documents included, and to be held in a setting readily accepted as a forum for education so that participants would look on the program as being a very serious matter.

Although the entire Macomb-Oakland community placement program is founded on ideology, normalization, and corollary principles, most actual learning objectives for training are practically oriented, not theoretical. For example, in the section on fire and safety considerations, one objective for the participants is, "Describe the most desirable manner to extinguish fires of paper, cloth, wood, grease, gasoline, lighter or cleaning fluids and assorted chemicals." Objectives like these help service providers to respond to a crisis before the crisis occurs. We don't want a fire to start and have people burned because no one knew how to put it out. Here is another example of a practical objective: "What is the first thing you would do upon discovering a fire in progress on a stairway leading to an occupied second floor? What's the second, third, fourth?" Questions like these, it is likely, would never be considered until it was too late.

The discussion stimulants are very important too because they help break up the monotony of didactic sessions with simulation experiences. For example, during the normalization session, we ask people to step in front of the class and role play problem situations. To illustrate: "A hardware store owner wants to give a swing set to a group home for six men. How would you deal with this? Would you call him a fool or would you educate him?"

Written references are probably the least valued element to the participants. Although we list the primary literature sources that our session contents are drawn from on the outline for each session, participants are not typically apt to go out and retrieve the readings from some library. So we bring in copies of the things we think are the most important and distribute them as reprints. Frankly, I am not sure if they're ever read, but even if they are not, I think the references help add more legitimacy to our training program.

Mandatory Training

We also decided in those early planning days that training would not be voluntary nor time limited. It had to be mandatory and ongoing. It wasn't going to be 6 weeks and it's over, or 100% on three exams and it's over. Training had to be compulsory and forevermore. In the Macomb-Oakland training program, whether a foster parent works for 5 or 10 years does not diminish his or her training attendance responsibility. It is mandatory that he or she come to training sessions on a monthly basis. We write contracts

with providers for the payment of services to clients who require room, board, supervision, and in-house programming. The contract also demands monthly attendance at training sessions. If you don't want to come to the training program, we cannot do business. It's not much more complex than that. We were told by many professionals that if we wrote this kind of an expectation into our contracts people would not be interested in providing community placements. But we took the chance, and it has paid off handsomely. We want our service providers to be knowledgeable. We want them to know more about first aid and more about behavior management than most social workers, more than our consultants. We want them to be experts. There is nothing to gain from our wanting anything less. We don't want people who are not interested in taking part in training. We don't feel that we need them. We don't want professionals who are threatened by individuals on their caseload knowing more than they do. We don't feel that we need them.

Training Costs

It is important to know the costs of our training program because people so often say that what prevents their putting on a good program is that they don't have Title XX money for training or they don't have a grant for the purpose or they cannot pay speakers through normal or abnormal budgetary means. Our training program does not cost anything. Nobody gets paid. There is no special financing, yet the program is excellent.

In the past, we have heard it said countless times that since there's no money, we just can't do it. How are you going to ask a fire marshall, for example, to come in and teach your staff fire prevention for free time after time after time? The answer is simple: you don't ask the same fire marshall each time! We ask favors and we do favors in return. We beg and borrow professional courtesies and it hasn't strained our relationships with colleagues because they view the program with respect and know how much we value their contribution to it. You tell me how many times a fire marshall would otherwise see his name in a printed introduction of a lecture series as someone who attended the Oklahoma Fire College and completed 8 weeks of asbestos training in Ypsilanti, Michigan. Tell me when that man is ever going to be held in as much respect as he is by those 20 service providers who want to know how to put out grease fires. The man is going to come to your ses-

sion with pride and enthusiasm, not mere resignation, and he is going to turn your participants on to learning important things—if you treat him right.

We've never paid a cent to anybody to conduct a training session. The closest we ever come to paying is buying hungry and thirsty speakers a hamburger and a beer after a training class. If speakers say they can't come back, we ask "Who can replace you? Can you tell us who can come in?" If they say, "I don't know," we say, "Look, we're in this together, you are part of it whether you participate or not." "Do you want it to end?" "We're counting on you to help us." That's not very professional, is it? It's not very dignified either, I realize that. It puts you in a rather compromising position. Who wants to ask for favors? On the other hand, the alternative is even less attractive.

Training Incentives

There are many incentives for the participants at our training sessions. The self-respect for having acquired knowledge that they get from training is an important consideration. They also receive something else that's subtle, but important: recognition. We have been very fortunate in our agency to receive a lot of positive publicity. We have had people come from hundreds of places across the country, and a few from other parts of the world because they have heard of the Macomb-Oakland Regional Center. When visitors arrive, like Allan Roeher from Canada, we take them out to see our foster parents. We tell our foster parents who he is and how important he is. Knowing that we are so proud of our community placements that we are pleased to show them off to visitors makes people feel pretty good about themselves and the work they are doing. How much does it cost? Nothing! It doesn't cost a cent, but this recognition is a very powerful incentive.

We have a disincentive as well. If you don't come to a training meeting, you lose the money you would ordinarily receive for providing in-house programming for a resident on that day, which usually amounts to about $10. This has only happened a few times without a legitimate reason. Although the situation has never occurred, if a foster parent missed three consecutive training sessions, he or she would be discontinued in the program. We would remove all clients from their service setting.

TRAINING STRENGTHS AND WEAKNESSES

Our training program has many strengths and some weaknesses. Its weaknesses include the potential to lose creativity and daily initiative. It is, for example, easy to become unimaginative in putting together learning objectives and in selecting resource people to make presentations. It is very easy to become lazy, and we have to constantly check ourselves against it.

It is also easy to excuse absences. "She had to go shopping, could not get a sitter," etc. At Macomb-Oakland, we believe that you have to be very ambitious; you have to sell the value of training to the people who attend. This is a critical factor. The participants have to appreciate the relevance of training content. We want them to know what to do when someone breaks a bone. They must know! It is very easy for social workers and others who put on training programs to take content, approach, and the effect of their own attitude for granted.

Our provider readiness training has allowed us to be aggressive in developing alternative programs. We prepare people to take the toughest kinds of clients; we teach them how to deal with these folks and we pay them fairly for their efforts. We make them accountable for their services, and we are accountable for ours.

Training also helps natural parents become infinitely more secure about community placement, and this is extremely important. It has been our experience that natural parents often view institutions as at least acceptable because they offer a kind of security in their citadel-like appearance, in their predictability. These parents also find comfort in the knowledge that institutional attendants "know" what they are doing. They have been trained. They might be understaffed and so forth, but they have acquired the special skills necessary to work with "mentally retarded" persons.

Because of our extensive training programs, we can now offer natural parents the same kind of security. Now we can say that our foster parents and group home personnel come to the job with more than good intentions and energy. They know what is expected of them and they are prepared to satisfy our expectations. Our foster parents and group home staff know what they are doing, believe me. This knowledge makes service providers and parents, as well as bureaucrats, more confident in the placement program.

Another subject that is important to placement success is language. Our professional jargon can be of benefit when we are discussing concepts with one another, but it can inhibit communication with people who have an interest in our field but are not part of it. People hear the jargon but are not privy to the translation.

We take pains to make sure that jargon used in human services—the acronyms, the abbreviations, the technical terms—are not foreign to our community service providers. When we ask a foster parent to work on a behavior management program, we want them to be familiar with the methods, the technological means as well as the long range goals. We make an effort to be certain that that foster parent knows what we are talking about. It becomes incumbent upon us to interest the provider in the monthly training sessions, to teach them what is involved in working toward behavior management objectives.

A fundamental understanding of the Macomb-Oakland Regional Center training effort is that we, agency professionals, are responsible for the education of foster parents and group home personnel. This tenet places the burden for client habilitation squarely on an identified agency and equally identifiable individuals within it.

Good training of providers virtually eliminates the phenomenon of clients returning to the institution because he or she failed to adjust.

The acceptance of the importance of training and the placement agency's responsibility to provide it places the burden on the right people. Training makes social workers and case managers stay sharp, makes in-house programming possible, allows us to pay foster parents and group home employees adequately, permits us to serve larger numbers of clients, interests more potential providers, makes parents more confident, and accelerates the client's movement toward independence. As we improve our training efforts, our efforts to prepare people who are part of the community placement scene, we increase the quality and the quantity of residential options to the institution. Ambitious provider training and successful community placements are inseparable.

CONCLUDING COMMENTS

There are additional considerations that have been important to the community placement success we have achieved at Macomb-Oakland. First, when we set out with the notion of making institu-

tional life obsolete, we did not begin by trying to alter the manner in which "mentally retarded" persons were being treated in the entire world, the United States, or even Michigan; just two counties. We began with something, an area and population, that we thought was manageable. Second, we decided that we were going to try to change, not merely improve, the system as it existed. In this regard, we felt that we could patch up the system in a number of places, make a few modifications here and there, and provide a service that most consumers would find acceptable, but not a service that we as professionals witn high expectations of ourselves and our resource capability could find acceptable. An improved system that is wrong in its focus is in need of change, not improvement. We committed ourselves to changing the focus. We felt that virtually all "mentally retarded" persons could live nicely in the larger community, so we established a goal of proving that the traditional institution was unnecessary. In keeping with this goal, we decided to work toward two key objectives: 1) returning 100 people per year from institutions to individually preferable residences within their home communities, and 2) having no new institutional admissions. A third very important early consideration was our decision to attack the attitude, or the assumption, that people living in institutions have to "learn" their way out. In 1972, when we went to an out-of-state institution and asked who was ready for community placement, the number didn't require a dozen moves. Hardly anybody was ready! They weren't ready because they hadn't been toilet trained, or they didn't know how to eat independently, or they couldn't dress themselves, or they had maladaptive behavior. They hadn't learned enough to leave.

If you will look, as we did a couple of years ago, at the professional literature and compare the attention shown to preparing retarded people to move out of institutions versus those dealing with the preparation of people who receive the institution's graduates, the ratio is alarming. Over the last 5 years, myriad articles have dealt with preparing clients to become competent enough to leave institutions. Three have treated the subject of provider readiness. There has been an unforgivable lack of attention focused on teaching foster parents, natural parents, group home people, volunteers, administrators, managers, and similarly employed people how to provide human management services in community settings.

We simply decided that we were not going to impose traditional readiness criteria on our institution's residents any more.

We no longer required clients to learn their way out. We thus eliminated an enormous quasi-legitimate barrier. We dumped it! We decided to place training emphasis at the other end of things.

A final factor that seems crucial from our experience was to establish a core group of workers strongly committed to two values: 1) a sense of urgency, and 2) a sense of responsibility.

We have never had more than seven full-time staff members developing placements and organizing training. We continue to meet frequently to reinforce one another's sense of urgency toward our mission. We remind each other that what we are working on has to be done yesterday, that we are writing history, and that we are making major contributions to future trends.

Numbers are important. If there are 1,400 people living, for all practical purposes, like non-citizens in one of our state institutions, they all deserve to come out. Not just seven in a perfect group home that meets all the normalization specifications. They *all* have to come out. We decided that we would do everything possible to create ideal living arrangements for every client, but our inability to create the ideal would not unnecessarily delay the return to the community of any individual living inappropriately within the institution. This sense of urgency is essential; people must be continuously reminded that the people depending upon the products of our labor will not live another lifetime.

By a sense of responsibility, I mean simply that you have to personally accept the obligation to make changes in the system. You and I have this responsibility. We do well to begin by identifying the impediments to change. Are they procedures and policies? If so, we must change the procedures and policies. These changes are made by you personally getting on committees, you personally writing letters, you personally bugging your boss, you personally having him bug his boss, you personally going to interagency meetings, setting up your own training program, putting the arm on people, or going a more diplomatic route, but convincing people to make positive contributions to your program.

We decided that we would never succeed as individuals or as an agency by saying things can't be changed because "that is how the system is." In what is perhaps a melodramatic fashion, we characterize ourselves as revolutionaries who have taken an oath to bring about critical changes in our interagency system and our fellow citizen's system of values.

It is a beautiful, thrilling thing to take on an almost impossible task of changing entrenched practices. The fanaticism flows. The job is so awesome, so outrageous, and yet at the same time so challenging, so invigorating, so poetic, so romantic. You might look at this and other ways we have accomplished things at Macomb-Oakland and judge some of our methods as unconventional or undignified. The fact of the matter is, however, that we have decided that traditional, professional behavior is just not suited to contemporary problems. We have decided to simply use methods that will work for our clients. In doing this, we have sometimes traded the conventional dignity of the professional for the ultimate dignity of the "mentally retarded" citizen. This has seldom proved a bad bargain.

QUESTIONS AND ANSWERS

QUESTION: Does the increased staff ratio in your foster homes over the institution make a significant difference in an individual's progress?

PROVENCAL: It makes a dramatic difference in the progress of the person who is now living in the community. The person who moves from the institution to the community gets 2 hours a day of training in the home. In addition, he or she attends school, a workshop, or a job in the community. An institution is not conducive to this kind of mobility. Additionally, in a foster home, you don't have a 1:4 or 1:8 ratio, you have one family to a maximum of three clients. Our average is 1.2 people living in each community training home, so it's relatively easy to devote 2 hours a day to tutoring.

QUESTION: DO you deliver the non-core classes in the same way as the core classes, and would you teach something like yoga?

PROVENCAL: Yes, we deliver the non-core classes the same way. If we had enough interest among people attending the inservice, we would bring in a yoga person, but it would just be a one-shot deal.

Questions: Did you say that your foster home cost is $25

per diem and that you could have three people at $60 a day?

PROVENCAL: Our total cost is approximately $25 per day per client. This includes administrative costs as well. Foster parents receive approximately $20.00 per day per resident. Three resi-

dents would earn $60.00 for a foster parent. We think that we place enough demands on the foster parents that the money is well earned. The cost of institutional placements in Michigan averages from $55 a day. Macomb-Oakland supported institutional slots cost over $100.00 per day. It is a bargain any way you look at it, and the quality of placement is just not comparable to the institutional placement.

QUESTION: Our rates are much lower than that. How can we doit?

PROVENCAL: Our programs were built on $11 a day per client for the total program. The new rates were a reward to us last year because we were doing such a good job. You can do it by deciding that you have to.

QUESTION: What about recidivism?

PROVENCAL: I mentioned that we've had 18 admissions, and that includes readmissions. However, we do have options. For example, take the person who acts out, say a large man who behaves in an aggressive fashion. We can send staff members into his group home, maybe using the same staff from back in the institution. This person might talk to the client, walk him around the block, or write out a new behavioral plan. We would have to do it when he came back, so why not try it before then? The other thing we can do is explore another placement for him. If he's got to move, let's look at some other community homes. Some people might say that moving him from one home to another is unsettling. It's a lot less unsettling to move a person from one group home to another than from a group home to an institution. These approaches have been very effective for keeping people out of institutions. Almost totally! I mentioned we have had 18 admissions. These mostly came in the first 2 or 3 years when we had few supports to rely on.

QUESTION: DO you use group homes and your community training facilities for your medically fragile, multiply handicapped as well?

PROVENCAL: Yes, we do. But we feel a need to expand and improve this service. From time to time when visitors come, they particularly want to see if we're talking about really highly dependent, multiply handicapped people moving into the larger community. We haven't placed as many people who are medically fragile as we would like, but we have placed many such people. This group makes up the largest part of the people who are remaining in institutions.

QUESTION: What about babies?

PROVENCAL: We're very fortunate in Michigan. Since 1972, we've had an extremely progressive special education law, which really took off about 3 years ago. We have mandatory special education for everybody from ages 0 to 26. Now, not all districts are performing, but since it is on the books, parents are educating themselves about the services due their child. The result has been that we have very few requests for infant services.

QUESTION: DO you have the same kind of programs for the people in the pediatric nursing homes that you have for the others?

PROVENCAL: It isn't the identical program. It is closer to an institutional program because it's more medically oriented. Nurses run it almost exclusively. We haven't given this sufficient attention as yet.

QUESTION: What sort of cooperation do you get from the parents of people you are placing out of institutions?

PROVENCAL: It really has gone up dramatically. In the last 5 years, we've only had one parent resist us right down the line on community placement. We've had hundreds disapprove in the beginning, but we get other parents to support us. We've made the parents who are most in favor of our program into salespeople. When parents resist, we ask our supportive parents to speak with those who are resisting. They are our best ambassadors. Who wants to listen to a social worker like me tell a parent what he or she should do with a son or daughter? What do I know about matters of their heart, their guilt, their desire for protection? How could I know? Other parents know and they can be extremely helpful during the deliberation.

QUESTION: What would you do if the state decided to expand the types of handicapped people you serve?

PROVENCAL: I don't think it would make much difference to us whether they expand, as appears to be the case, the definition of those eligible for service. It will give us a new group to serve and we will have to learn some new things. The critical point is that we are committed to providing alternatives to institutions. If group homes and workshops are too institutional, the next movement must be to change them. I think we can replicate with other disability categories the things that we have learned through working predominantly with "mentally retarded" persons. We have been approached by groups like United Cerebral Palsy and the Epilepsy Foundation to help develop segregated group homes.

We've declined to participate. Segregated, exclusive homes for these populations would be easy to do, but wrong. Instead, we have provided these groups help in developing more integrated services.

We've developed 30 group homes in 4V2 years. Now we know that we have too many group homes. We still don't have enough people out of institutions, but we have developed too many group homes. We don't want to create more segregated services, even group homes. We have to go further. If your group approached us with a desire to develop residential alternatives for autistic children, we'd probably help you set up foster homes, with the foster parents trained in accordance with our community training home model, or help you work with natural parents in some similar capacity.

QUESTION: What kinds of experiences, if any, have you had with community resistance?

PROVENCAL: We've had quite a variety of experience concerning community resistance. I have several opinions about it. One is that it's very easy to get turned off and have your efforts blunted because you've raised the ire of property owners. We've been turned down in asking for zoning exceptions a dozen times. We have had bloody battles and we've had battles where there was no bloodletting whatsoever. Sometimes you cannot even tell who your opponents are. We also have had some wonderful experiences where we've been able to turn around entire neighborhoods. Occasionally, when a provider vendor has found an especially good home, we have been able to go and talk to the neighbors and tell them the difference between our clients and what they think they are. Many people, for example, still confuse "mentally ill" and "mentally retarded" individuals. They take the most extreme examples of one category and apply it to the most general member of the other category.

It is an easy, obvious excuse not to open a home because property owners will not let you into their neighborhood. But there are all kinds of neighborhoods out there where they will accept you. If you happen to pick on a neighborhood where the zoning isn't right, there are other neighborhoods around. There are millions of homes in our area. Why get turned off entirely because one group turns you off? Anyway, it may be a blessing in disguise. As Wade Hitzing says, "We shouldn't have six sailors or six chorus girls living together." Why fault the community? Let's start working toward only having one and two people living together. That's what we should all be about anyway.

We also have an obligation to do a number of other things. One is that we have to continually educate everyone and not just the guy who is trying to fight us. Macomb-Oakland Regional Center makes an all-out attempt to influence newspapers, and we make sure that they print what we want by sending them newsworthy stories that are positively oriented. We frequently make contacts with reporters for the purpose of educating them to our goals, our problems, and our needs. We've made a very concerted effort to do these things, and we have hundreds of positive articles printed every year.

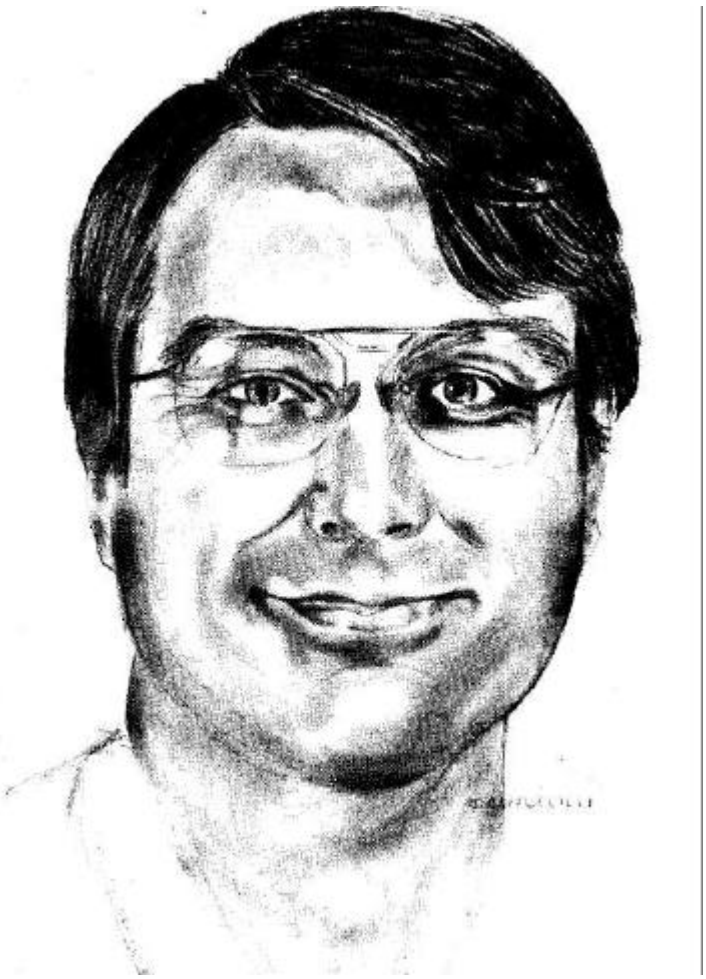
QUESTION: I don't see how we could replicate your program in Los Angeles. It's too big. Our hospitals have thousands of people in them.

PROVENCAL: We are dealing with hundreds of people in our catchment area. Without question, your problem is much larger. Some of us had an opportunity to work in New York on the Willowbrook Plan. They told us that we "white-socked hicks" from the Midwest could in no way understand the "Big Apple," and that our service concepts really should be left in the boondocks. Willowbrook's problems were considered too complex. They kept talking about the bilingual problem, the Staten Island Ferry, and other things that we really didn't have any understanding of. But we decided that the principles we had were universal, and that the program concepts we had, although they weren't terribly novel, had any number of variations. For example, if it's not a group home for eight people, why not have a group home for four, or why not apartments? Why not look to apartment owners? I understand Philadelphia, Pennsylvania has been a pioneer in making use of apartments. Why not have your social workers go around and visit people in their apartments? Why not develop core residential units where you have one group home that supervises people living in their own apartments scattered around the city? There are people who are a lot more imaginative than I am who can devise any number of residential concepts to meet your needs. Macomb-Oakland is moving away from traditional group homes. We are looking for better things. We would still open a group home to get eight persons out of an institution, but we would rather see program models that are more normative.

In any case, there are answers for Los Angeles. You just have to look for them.

Wade Hitzing

ENCOR AND BEYOND



work at the Center for the Development of
Community Alternative Service Systems (CASS), located at the Medical Center of the University of Nebraska. It is affiliated with the Meyer Children's Rehabilitation Institute, CASS exists to provide technical assistance and training so that "developmentally disabled" citizens will have the same residential, vocational, educational, and social opportunities available to all other citizens. It provides program and manpower development assistance throughout Federal Region VII: Nebraska, Kansas, Missouri, and Iowa, CASS works with community-based service programs, community colleges, and universities to help establish broad-based training networks.

CASS employs four community service specialists. They assist the community programs in our region to develop high quality integrative services for developmentally disabled citizens. Our services range from assisting a State Planning Council in preparing its annual plan to going to Sioux City, Iowa and testifying before a zoning board for a residence whose opening is blocked by an objecting church, CASS does not offer direct services. We suggest

how things ought to be, help write out service plans, and then drive back in our air-conditioned Medical Center car, leaving the service and advocacy groups with the difficult job of actually implementing the plan.

I had the good fortune to serve as the Director of the Division of Program Development and Training for the Eastern Nebraska Community Office of Retardation (ENCOR) for 1 year during 1975 and 1976. Many of my comments in this chapter focus on lessons I learned from observing ENCOR'S experience in community program development, especially in the area of residential services.[1]

THE ENCOR SYSTEM

State Organization

An overview of the ENCOR model is provided in this section. The organizational structure for Nebraska's services for persons labeled "mentally retarded" is shown in Figure 1. The Department of Public Institutions administers Nebraska's one state institution (recently labeled the Beatrice State Developmental Center) and the Office of Mental Retardation, the state regulatory agency for community mental retardation programs.

Nebraska's community service system is divided into six regional programs, ENCOR is located in the eastern part of the state, Region VI. This region includes only about 3% of the state's total area. However, approximately 35% of the state's population, 1.5 million people, resides in ENCOR'S service area. Enormous demographic differences exist among the five counties included in ENCOR'S area. It encompasses urban Omaha, which is fairly typical of any relatively large city, and areas in outlying counties that are very rural. The total case load for ENCOR during the period 1976-1977 was 541 adults and 350 children. Table 1 summarizes the number of clients who received services purchased or provided by ENCOR.

ENCOR's Organization

The administrative structure of ENCOR can be seen in Figure 2. A commissioner is selected by each of the five county boards comprising ENCOR'S service region to be on the governing board for an

[1] 'Ed Skarnulis was Director of Residential Services at this time and provided much of the information in this chapter.

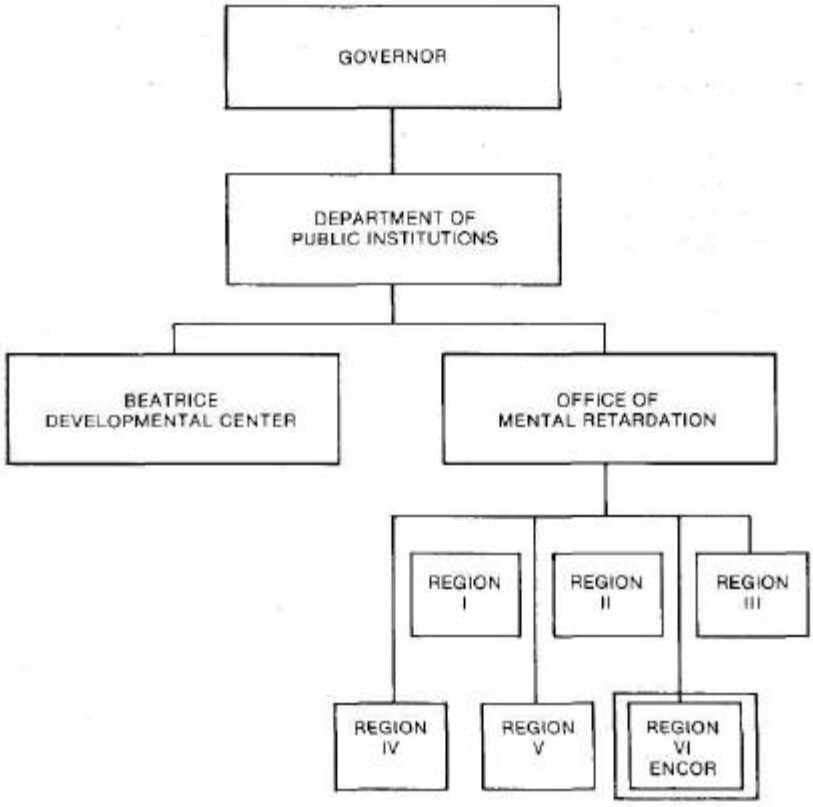


Figure 1. Nebraska's service structure for the "mentally retarded."

Table 1. Number of children and adults receiving ENCOR services in fiscal 1976–1977

Service type	Children	Adults	Total[a]
Residential	102	149	251
Educational	146	4	150
Guidance	350	541	891
Specialized	176	176	352
Transportation	99	165	264
Recreation	0	0	0
Motor development	149	99	248
Vocational	3	315	318

[a]Duplicated counts of clients in every service they received throughout the year.

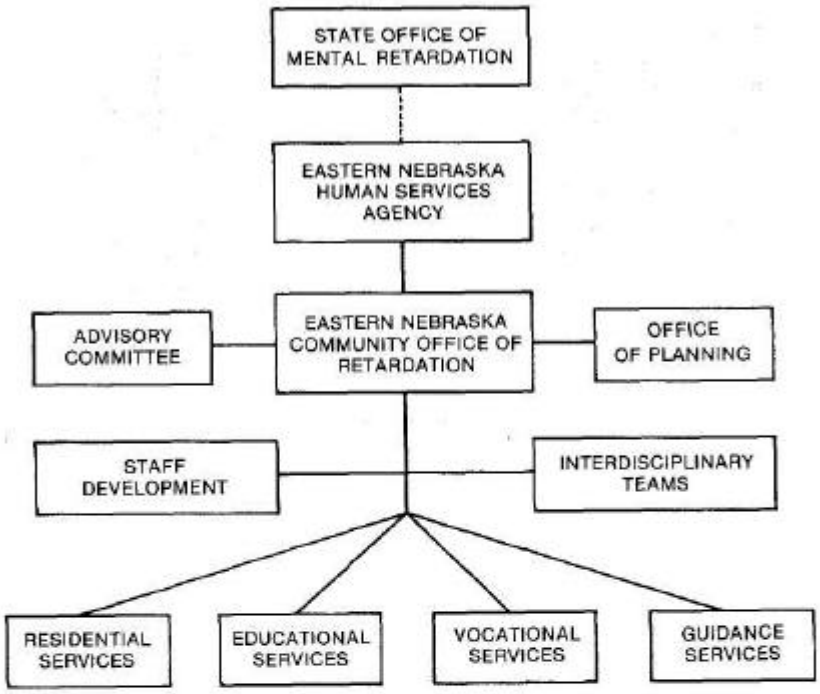


Figure 2. Organizational structure of ENCOR's regional community program.

umbrella agency, the Eastern Nebraska Human Service Agency (ENHSA). ENHSA includes the Office of Aging, Office of Retardation, and Office of Mental Health. The members of the ENHSA governing board set administrative policy and approve major decisions. The director of ENHSA has administrative responsibility over the ENCOR director. ENCOR is suborganized into residential, educational, vocational, and guidance service divisions. The other functions shown provide support to these divisions.

ENCOR'S RESIDENTIAL SERVICES

Overall Organization

The organizational format for ENCOR's Residential Services is illustrated in Figure 3. The personnel who operate this system include one division director and four area coordinators. Each coor-

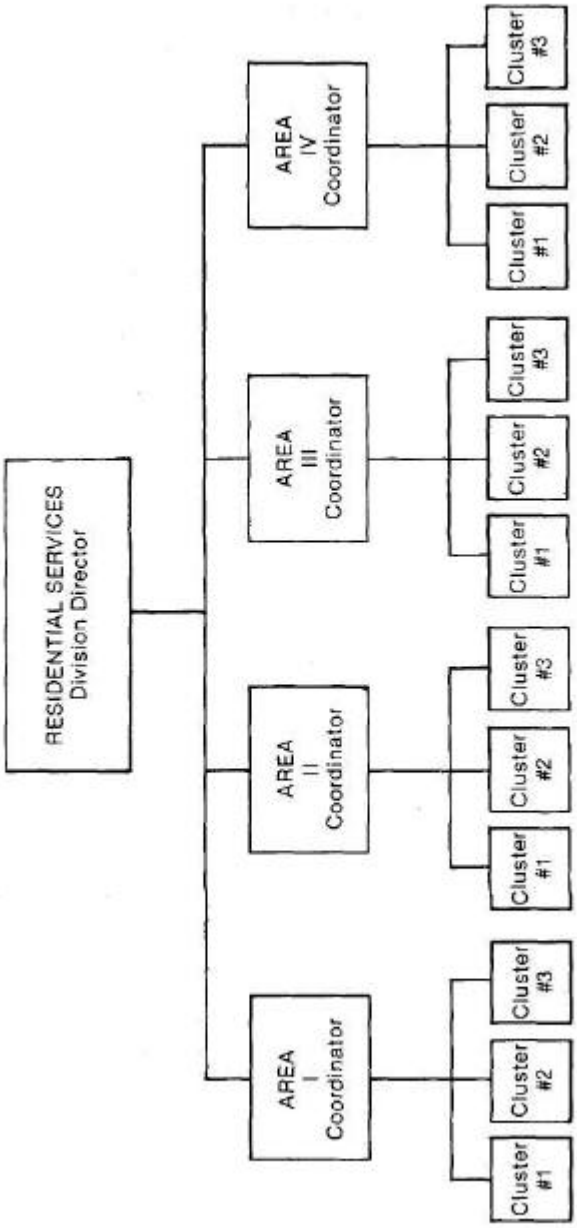


Figure 3. Organizational structure of ENCOR's residential services.

dinator is responsible for a number of geographically dispersed clusters. A cluster consists of a core training residence, serving usually three to six clients, and an array of individualized placements (alternative living units), which spin off each core residence. The staff for each cluster includes a manager, who primarily works out of the training residence, an assistant manager of the core residence, an assistant manager of dispersed services, and line staff. The assistant manager in charge of dispersed services has primary responsibility for supervising and providing support to the alternative living units organized by the cluster: apartments, condominiums, independent living arrangements, and foster homes. Line staff are called "residential assistants," a title that has changed many times during ENCOR'S history.

One factor that differentiates ENCOR'S programs from those operated in other areas of the country is that ENCOR is a monolithic system, ENCOR doesn't contract with private residential vendors. The staff person who goes out to a client's apartment once a week and the staff member who works 40 hours a week in a training residence are both employees of ENCOR. Foster parents are also ENCOR employees.

Core Training Residences

ENCOR'S core training residences range from large group homes with capacities of up to eight residents to small houses with three clients. People with disabilities come to core residences as a transition to more independent, individualized community placements. Core residence staff recruit, train, and draw up contracts with community members who are interested in providing community residential placements. Community members are recruited by newspaper advertising, notices posted at universities, United Way, radio and television advertising, and church announcements.

Each training residence serves as a central "back-up" and support mechanism for all of its individualized placement settings. Residential assistants go out from core residences to provide support for alternative living unit staff, and core training residences, along with contracted community homes, serve as temporary back-up placements when crises occur.

Alternative Living Units

The design of alternative living units ranges from live-in staff in an apartment with one or two clients to off-site staff support for

individual clients on a daily, weekly, or monthly basis. No two alternative living units are exactly alike. One of the more famous ENCOR alternative living arrangements is the Developmental Maximation Unit, located at the County Hospital, which serves multiply handicapped, medically fragile children. Most children are placed in nontraditional foster care settings, which may overcome many of the difficulties of typical foster care. Foster parents are provided with adequate training, and are contracted with to provide clearly defined services. The point is to try to employ indigenous community homes as placement sites and community members as program staff because doing this results in a more normalized approach to human management.

With no mandatory staffing patterns, salaries, regulations, fire codes, or architecture, you can't find an alternative living unit unless you know where to look, ENCOR has found that communities are filled with people who are able to share and teach. With adequate pre-screening, continuing training and supports, and decent wages, people can be mobilized to use their own homes and apartments to offer high quality, integrated services and individualized, in-home training. The alternative living unit model works because people in natural communities can develop skills to support handicapped people in their progress toward more independent living.

In-Home Services

ENCOR'S residential division also offers in-home services to natural families that range from babysitting to direct work with parents on changing a problem behavior, to crisis in-home support, ENCOR operates on the policy that no external residential service can duplicate a young person's healthy family system. The bond between a person and his or her family weakens when they are separated by distance, for long periods, or if they have to live with large numbers of unrelated persons. Supporting the family early is important. Parents are encouraged to identify their needs for relief periods, counseling and support, in-home training, short-term crisis assistance, or special appliances in the home. With adult clients, the important issue is to support the family's efforts to help the client achieve independent living, ENCOR helps parents to assist their adult handicapped offspring plan for a job, find a home, and live as normal and as independent a life as possible.

ENCOR has found that it is less expensive and more effective to support natural homes with a wide range of backup services than to remove people from their homes and serve them elsewhere. When a decision is made that a child or adult must leave home in spite of all supportive attempts, every effort is put into finding a community placement close to home, ENCOR staffs work to find as integrated a setting as possible with the shortest length of stay possible. If the move must be permanent, great care is taken to avoid placing the person into an institution. The important thing is to find an alternative residence that supports the fullest development for the person in the most integrated setting possible.

Staff-Client Ratio and Costs

The staff-client ratio in ENCOR'S residential settings varies tremendously depending on the nature of the service being delivered. Five or six full-time staff members, for example, may operate a group home for three children with severe behavior problems whereas one part-time staff member may serve as a supervisor/visitor for 6 to 10 semi-independent clients. Client costs also vary widely but are relatively easy to relate to each client because of the *individual placement* approach. Fees for services range from $100 per day at the Developmental Maximation Unit to $20-$30 per day in core training residences, to $10-$40 per day in alternative living units, to $0.50 per day for periodic in-home services (these are best estimates possible as of December, 1977).

BASIC RESIDENTIAL SERVICE ISSUES

ENCOR'S experience in community service development offers a number of important lessons for those interested in developing alternatives to institutions. First, the history of ENCOR underscores the relative importance of philosophy versus technology in achieving advances in service development. Second, the experience of ENCOR, and other advanced, community-based systems, advises against developing a permanent, facility-based service continuum. More flexible service systems are needed. Third, ENCOR has learned that high quality residential services must be designed and delivered on an individual basis. Finally, ENCOR'S experience strongly suggests that we should begin by developing the most integrated aspects of service systems and only develop specialized services when absolutely necessary.

Philosophy versus Technology

We've found that one of the major stumbling blocks to community service development is a lack of understanding or commitment to appropriate program philosophy. For example, when Federal Judge O. Judd in the Willowbrook case was asked why so many "retarded" citizens live in Willowbrook, he had a simple answer: "There's no other alternative!" The fact that no other alternatives existed in the state of New York at that time had nothing to do with the technology of human services, nor had it anything to do with knowledge of how to run residential programs. Rather, it had to do with the basic values and program philosophy of the service system.

About 10 years ago I was involved in a behavior modification program at Kazamazoo State Hospital. I thought that if the hospital could reduce its population by 30% during the 2 years I was there, it was going to be due to the efforts of our behavior modification program. It surely wasn't! The population was reduced by 30%, but it was reduced because the department simply adopted a new philosophy of residential service. The new philosophy said, "We're not going to do this any more; large congregate institutions are not viable service units. We're moving away from them." This change took place because key decision makers changed their *basic program philosophy.*

I don't know of a single situation in which system changes were primarily motivated by technology. Sound teaching technology does have to be available in order to integrate children with special needs into normal school programs. Technology provides means and procedures, but it does not provide goals and objectives. You have to be able to change behavior, but simply knowing how to change behavior is not sufficient in itself. The development of quality programs depends on a guiding philosophy and a commitment to implement it. In ENCOR'S case this philosophical perspective encompasses three basic components: 1) assurance of legal and human rights, 2) adherence to the developmental model of growth and development, and 3) actualization of the principle of normalization in human services.

It is very important to use philosophy as a guidepost when devising program technology. When I first arrived at ENCOR we asked our vocational programs to evaluate their services. Service providers knew lots about outcome data; they were already plotting various indices of clients' behavior. Radical behaviorist con-

sultants had six-cycle charts pasted all over their walls and were selling wrist counters. These service providers knew outcome, but often there was little emphasis on how to get there, and little recognition that the nature of the means is just as important as the objectives being sought, ENCOR has achieved major changes in this area. These changes are reflected in the agency's policies and in the ways behavior management procedures are applied, ENCOR has allowed basic program philosophy to influence technology as much as possible rather than vice versa. Some of the evaluation questions that we are beginning to ask ourselves in this area are included in Figures 4 and 5. If a 35-year-old adult is being given M&M's as reinforcers at 2:00 p.m. in a sheltered workshop setting in order to learn how to put on his pants, you've got some serious questions to ask—even if he learns how to put on his pants. A recent personal experience reinforced how important philosophical considerations are in developing sound service programs. I served on a task force to plan a residential program for 12 children with severe disabilities. These children were going to school 5 days a week at the Medical Center in Omaha. Their residential program had been operated in keeping with the medical model at one time, but had been recently changed to a group home approach. The children weren't moved from the Medical Center. Instead, one large "group home" was set up on their ward. The task force agreed that we wanted to move away from this "group home" approach and that individual placements based on individual needs were in order. As we started reviewing all of the children's needs, however, I soon realized that we easily could have ended up moving them all to Beatrice Developmental Center. That's right—by carefully listing all the children's needs and the ways to meet them, we could have ended up moving them all to a state institution. Fortunately, the members of the task force were committed to certain fundamental principles of service development that dictated an alternative course of action. The program that we designed calls for individual placements in foster homes.

Problems with a Continuum Approach

The overwhelming acceptance of the "continuum of services" concept is proving to be a problem. States and communities are saying, "We must develop a continuum of services in order to meet all the needs of our handicapped citizens." These continua are almost invariably organized around different environments like those

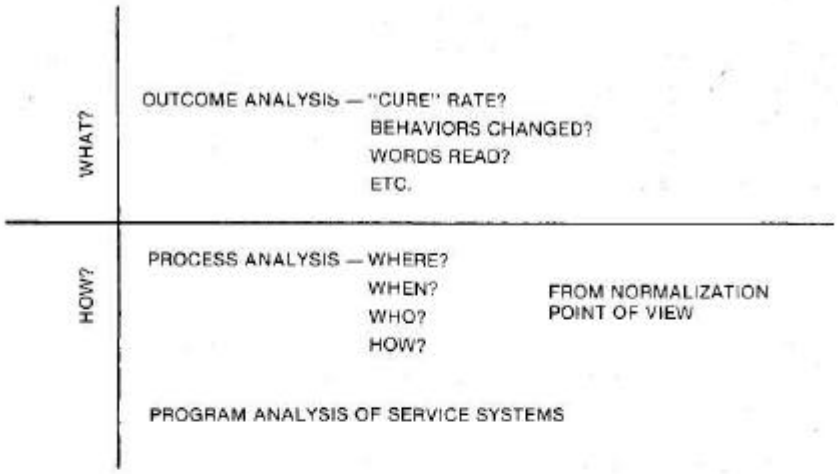


Figure 4. Program evaluation considerations based on behavioral technology and the principles of normalization.

depicted in Figure 6. The notion is that since a geographical area has X number of profoundly, severely, and moderately disabled citizens, you need Y number of work activity centers and Z number of sheltered workshops. This logic makes it very easy to develop a state plan.

The development of a residential continuum generally has advantages over the previous alternatives: institutions and supported natural homes. I see serious problems emerging in community development, however, if we continue to focus on developing service continua composed largely of specialized facilities that place people in different living environments on the basis of certain labels or classifications. Some day we will be faced with

REINFORCEMENT RELATED	NORMALIZATION RELATED
1. EFFECTIVE REINFORCER?	1. AGE APPROPRIATE?
2. IMMEDIACY?	2. PHYSICAL CONTEXT?
3. FREQUENCY?	3. TIME OF DAY?
4. SCHEDULE?	4. DEVIANCY JUXTAPOSITION?

Figure 5. Evaluative criteria based on behavioral technology and the principle of normalization.

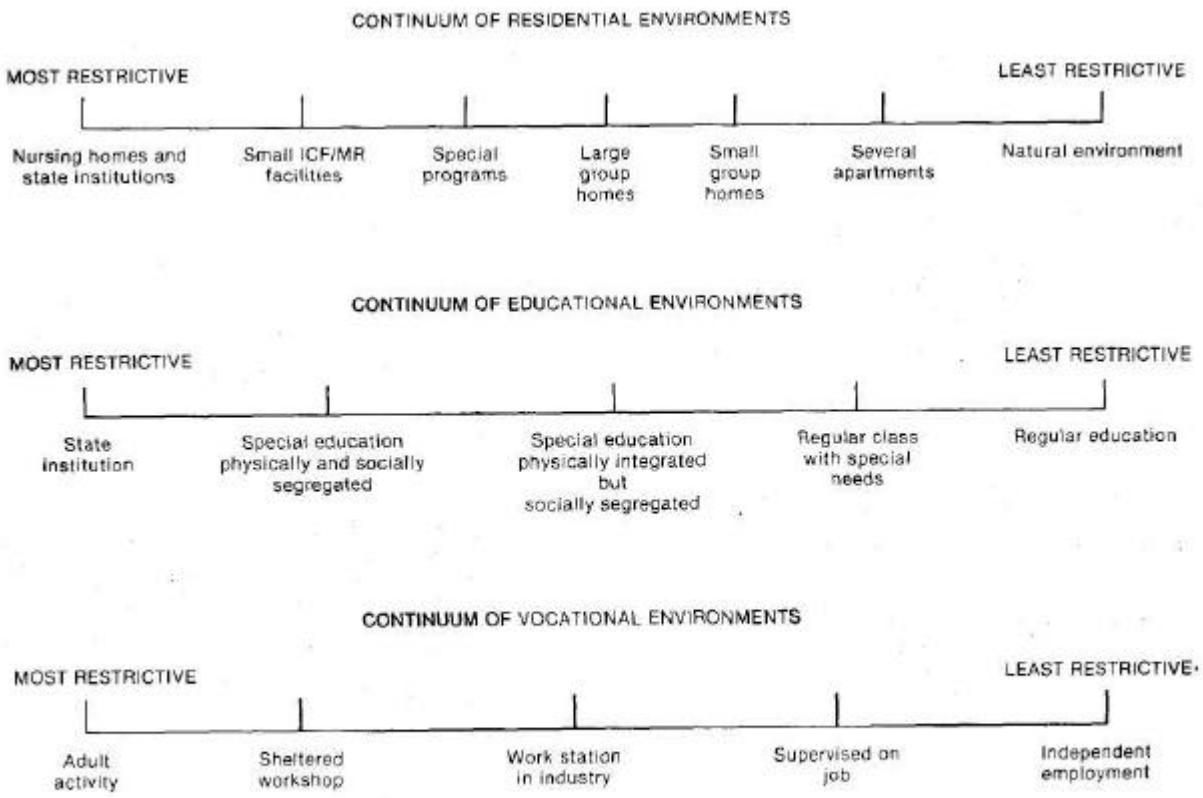


Figure 6. Typical service continua of residential, educational, and vocational environments.

changing these facilities and doing so may not be easy. For example, in a small town in Iowa $600,000 were invested in building a new addition to the county care facility. The addition was to be used, supposedly, to meet the vocational needs of the people who lived in the facility. Later, a proposal was brought to the county commissioners to fund a more physically and socially integrated vocational training program in the downtown area. The county commissioners said, "Two years ago you convinced us to put $600,000 into the county care facility and now you want $6,000 a year to rent something else. We built you a fine facility 5 miles outside of town. Go there." So now all of the city's vocational training programs are going to be 5 miles outside of town, a further barrier to the vocational integration of disabled citizens.

Another negative feature of most service continua is that they place a tremendous burden on *clients* for movement. For example, one state plan I read recently used the word "graduate" a number of times, always in quotes. The notion was that a person moved into the residential system initially by being placed in a nursing home or large group home. Once clients "shaped up," they "graduated" to a smaller group home. If they learned certain skills in the group home, they "graduated" to a more independent placement unit. The very existence of such a continuum of facilities forces the client to earn his or her way through the system. The underlying philosophy of this model is not at all consistent with civil rights decisions in other areas. The Supreme Court ruled in the 1960s that Black people had a right to ride in the front of the bus and to go to their neighborhood schools, rights based simply on their citizenship—not rights they had to earn. But with "developmentally disabled" people we have said you must *earn* the right to live in an integrated setting. You must behave yourself before we'll ever give you this right. This is clearly a basic form of discrimination.

Another reason for caution in our rush to develop service continua is that good services change over time in response to shifts in client population and in response to societal needs and opportunities. One critical factor contributing to the success of ENCOR is that its service system is designed to be flexible. It adopts residential models that reflect newer, more progressive thinking, ENCOR'S residential services were originally set up along a relatively traditional group home model. The core cluster-individual place-

Figure 7. Community-based services needed by some adults with special needs.

ment concept was adopted to allow more individualized, integrated modes of service. There has been movement from reliance on a "couple" houseparent role to a more professional staff approach, and the introduction of a more complex geographical regionalization-cluster approach to system management. The system also now serves more severely handicapped clients than in its early years.

ENCOR is beginning to meet clients' needs by doing away with the continuum. Maybe a continuum is necessary to meet your needs at some point in time for development, staff, and funding. Instead of saying that we must have eight different kinds of living places for handicapped people, however, try to have each person live in the most natural setting possible. For a child this means the natural family or at least a foster home; for adults it means living by themselves, with other adults, or whatever arrangement they choose. Many adults need supportive residential services. There must be 50 or so supportive services that adults with disabilities might need at one time or another in order to maintain a chosen living arrangement. Some of the more important of these services are outlined in Figure 7.

Individualization and Integration

All residential service decisions should be based on analyses of: 1) basic program philosophy, 2) the individual client's strengths and needs, and 3) the available placement and support options. There are tremendous implications for a residential system if you don't assume that everybody needs out-of-home services. It has implications for questions like when the service is provided, what type, whom it is provided for, and where the service is provided. For example, if a child needs a program because he or she roams at night, disturbs the neighborhood, or causes other problems that the parents can't handle, then the residential service must be provided in the home. The family's problems will never be solved by replacing the home. Ed Skarnulis (ENCOR Residential Director) told me about the case of a child who lived in an ENCOR residential placement 5 days a week and went home each weekend. Somebody finally asked why the child couldn't live at home all the time. They learned that the only reason the child was in an out-of-home program was that his mother had a job as a bartender and could not be at home from 3:00 p.m. to 11:00 p.m. Because she could not afford a babysitter her child was forced to live 5 days a week in a group home. Arrangements were made for babysitting services and the child moved out of the expensive, specialized residence back into his natural home.

Analyzing the reasons people are moving into your residential programs can tremendously influence your service program. If a child or adult is in your program because of a problem in the home, then this consideration should affect your service. You can implement a thousand behavior management programs for a person without making any impact on the reasons that person moved out of the natural home. Moreover, the person may stay in your program forever because you are not attacking the real reason for initial placement. People often automatically assume that it is acceptable practice to supply residential services simply because a person is labeled "severely handicapped" or "behavior disordered." Residential services are rarely questioned as long as the client has a label. But my observations of the ENCOR program have convinced me that the real reasons for placement are related to the *needs of individual clients* and to the *needs of their families.* Children with histories of not being toilet trained for 5 years are suddenly referred for out-of-home placement. Why after 5 years are

parents now seeking residential services? It probably has something to do with their current status: a divorce, illness, or additional children. The real problem is generally the lack of supportive services available in the family's community. Every case must receive individual consideration.

Planning Issues

Let's reflect for a few moments on what is happening in the area of social integration. I firmly believe that the war between institutions and community programs has been won. If I were going to invest my money in Nebraska so that I could buy a car next year, I might invest it in the Beatrice State Developmental Center, because Beatrice is still going very strong. But if I wanted to invest my money to retire, I would not invest it in Beatrice. The strong anti-segregated institution stance of Section 504 of the Rehabilitation Act of 1973 and the recent outcome of the Pennhurst case signal the long-term demise of state institutions. Section 504 maintains that all programs that receive federal money, benefit from federal service, or utilize federal property must serve handicapped citizens in the most integrated settings possible. It forces the service program to demonstrate that segregated services are necessary to meet the client's needs. The Pennhurst decision states that it is illegal to provide services to mentally retarded citizens in institutions like Pennhurst State Hospital and mandates shutting down this large facility.

I'm pleased by the decline of the institutions, but I'm concerned that we are not developing fully integrated community alternatives to take their place. It is important to begin planning and development of truly integrated service programs. We might do well to make the naive assumption that every disabled adult who comes from our service area can live in the community and can work in some business or industry or go to school with nondisabled classmates. If we start there and it later becomes necessary to compromise and use some segregated programs, we'll know that the compromise is really based on the system's needs and not on the client's needs. For example, we may have to meet a specific child's needs by placing the child in a special training home. But we must recognize the reason(s) for this compromise, i.e., the fact that this is the only program available right now, this is the only kind of funding we can get, the parents are fighting us, or our com-

munity staff isn't adequately trained. The worst thing that I see in communities is that often such compromises are rationalized as being based on *client needs.* This approach removes any motivation to ever change things. If most programs really adhered to their mission statements, in which they say they don't serve people who could be served in less restrictive settings, they wouldn't serve very many people.

Along with many others, I have been involved for a number of years in developing community alternatives to institutions, and I have been proud to be involved in this work. Co-workers and I sometimes sit around and pat each other on the back. "We are developing alternatives to institutions; aren't we good people?" Many of the people we serve have had to live in 2,000- and 3,000-bed institutions, but now we are developing group homes in their home communities. That's fine. However, another way of looking at these same community programs, which ENCOR has begun to realize, is that specialized programs, whether group homes or sheltered workshops, really serve as alternatives to existing, more integrated, generic programs. They may be more integrative than large institutions but they are still different than those available to all other citizens. We must strive to provide only those specialized services that handicapped individuals cannot get through utilizing generic services.

An analogy may be drawn between providing residential services to people with severe disabilities and attempting to make a regular hospital a nice place to stay. You'd have at least two vastly different ways of doing it available to you. One would be to take the hospital as it currently exists, bring in some architects, service providers, consumers, and look at the hospital and say, "Let's make it nice." You'd bring in potted plants, paintings, but you still wouldn't have a place where you or I would like to spend 5 days of our life. We could do something else, however. We could renovate the downtown Hilton Hotel. It doesn't have any surgery rooms or any sterile rooms so we would have to construct them. We wouldn't construct more of these rooms than we need, however, and I think we could end up with a place where we would like to stay. There is one hospital like this in Connecticut, and people wait in line to go there.

The long-term dangers of developing facility-based service continua are tremendous. We talk about skyrocketing institutional costs, but look at the costs of developing an extensive resi-

dential continuum. Find or construct a building, buy or lease it, furnish it, place clients, and assign staff members. By the time you get to the most integrated end of the continuum, the least restrictive segment, there are no money, staff, or clients. All the clients have been placed in group homes and the group homes cannot operate with fewer people. The outcome you frequently see in residential and vocational programs is a lack of staff for placement and follow-up when a client moves to an apartment or gets a job—almost all of the staff is used to run the segregated programs.

Although you necessarily may have some segregated programs at first due to funding constraints, eventually more integrated alternatives must be built. If the segregated programs remain on the continuum, people will be placed there, there's no doubt about it.

Clearly, the existence of already segregated community programs is going to be a barrier to the development of integrated service systems. In some states the barrier is lack of funds, but in most states it's that the wrong funds are available (i.e., Title XIX). In our region we still have the problem of existing laws and regulations as barriers. Because of Title XIX funding parameters, more beds and cottages on the grounds of institutions are under construction. Many states have reached the ceiling of their Title XIX monies and community programs are being cut back rather than expanded. The issue is not that we don't have the needed resources; it's a matter of where we are putting our resources. A number of states are going to make strong moves toward using Title XIX to establish highly integrated community programs. Our reading of the rules and regulations says nothing about not being able to use Title XIX funds to start integrated programs; the barrier is simply existing federal, regional, and state interpretations.

STAFF DEVELOPMENT

One important thing to understand is that although ENCOR has been viewed as providing exemplary residential service, it has never had an outstanding training program. In fact, I don't know of any community-based program in the United States that does. If there is one aspect of community service development of which we should be ashamed, it is training. The state hospital that I

worked for in Kalamazoo may not have always trained people to do the right things, but they surely had a serious commitment of money, time, and people toward training.

The training personnel for ENCOR'S staff development programs currently include one director and three trainers. Staff training begins with an orientation to the ENCOR system. This orientation covers system relationships; the history of attitudes toward and services for the "mentally retarded"; and other areas, such as human and legal rights, behavior management, precision teaching, normalization, and individual program plan development. This orientation is followed within 3 months by a 1-day session of normalization and PASS. Additionally, during the course of their first year, ENCOR employees attend 1-day training sessions on behavior management, writing behavioral objectives, and individual program planning. Most information is transmitted via lecture. A few slide shows, videotapes, and movies are used. Written handouts are supplied to supplement lecture content.

ENCOR, like most service programs, operates on the assumption that if you've received *X* hours of instruction, you're trained for something. There are obvious weaknesses associated with neglect of competency-based instruction. The unique thing about ENCOR, however, the thing that has always impressed me about the system, is its tremendous commitment to philosophy, both in its training and its service programs. I think that the widespread philosophical commitment on the part of ENCOR'S staff is partly attributable to its training program but more to the fact that its leadership mandates and models a strong commitment to "normalization."

Before coming to ENCOR I worked in Michigan trying to train hospital staff in behavior management. My dream was to go into a community agency or a hospital and teach staff members to talk about shaping, fading, and schedules of reinforcement to such a degree that it permeated their whole existence. But this strategy totally failed to make meaningful improvements in clients' lives. When I came to the ENCOR program I was hit right in the face—they had done it! They were helping clients achieve more independent and productive lives primarily because of a radical commitment to a philosophy—normalization. I think this approach may be easier. You first need to get the staff excited about what ought to be (philosophy) before you can talk about how to achieve it (technology).

The biggest reason for staff turnover may be that people don't understand what they're getting into. One important aspect of training for ENCOR'S residential staff is an early session where staff members talk about what it is like to be a residential assistant and what it is like to be a residential manager, ENCOR has learned to be honest early about what new staff people are getting into, and this has helped reduce staff turnover later.

One of the key factors in deinstitutionalizing the service systems may lie in learning to deinstitutionalize training. Once, while I was writing a paper on this topic, I began making writing mistakes. The mistakes I made involved substituting *service words* for *training words* because the fundamental issues are the same. If you live in western Nebraska and you want to be trained to work with disabled citizens, you have to move away from your home community. You have to fit into an existing career preparation system. They don't write individual program plans for you. We must develop deinstitutionalized strategies for training staffs just as we must develop similar strategies for serving clients. Heavy emphasis should be placed on field-based training; i.e., on delivering training in real community service contexts. Decades of research on transfer of training indicate that maximum generalization occurs when training is delivered in real versus classroom settings or simulated settings.

Finally, the two major problems I see with respect to training residential service staffs are appropriate or nonexistent curricula and insufficient application of good educational technology. Curriculum materials are not available in many areas and what does exist is often inappropriate ideologically or technologically. If you know of a film on epilepsy that presents technically correct information and shows clients in normal settings without a medical model, "sickness" approach, let me know. I don't know of any. Much work is needed in the areas of curriculum development and instructional technology, particularly with respect to serving "severely handicapped" citizens. I recommend the staff training materials recently developed in California known as *Way To Go* (1).

CONCLUSION

This chapter has centered on the structure of the ENCOR service system and on lessons to be learned from ENCOR'S experience. I

have attempted to emphasize: 1) the relative importance of basic program philosophy over technology in service development, 2) that it is a serious mistake to develop a continuum of different residential environments, 3) that services are best designed for and delivered to clients, and 4) that flexible, *specialized* services should be developed only when all attempts to utilize generic services have failed. The future of community-based residential services seems very bright. It will be all the brighter if we can learn from each other—from our failures and successes.

QUESTIONS AND ANSWERS

QUESTION: What sort of parent cooperation and involvement does ENCOR receive to convince resistive parents to move their sons and daughters out of institutions?

HITZING: As you may be aware, ENCOR was begun by the Greater Omaha Association for Retarded Citizens, ENCOR was eventually spun off from this parent group as it got bigger. Parent confidence in ENCOR'S programs is very strong. Parents are probably the strongest force in getting other parents involved in the program and in overcoming initial resistance.

QUESTION: Most of your efforts are with clients who have special needs associated with mental retardation. My agency serves clients who manifest other handicaps, such as autism. Can one service program serve all clients?

HITZING: Categorical programs don't seem to be necessary. A large number of clients in the ENCOR system have other disabilities. If you were diagnostically precise about it, the primary disabling condition of many ENCOR clients would be autism or some other categorical distinction. These clients are served, however, because ENCOR tries to provide as individualized a service as possible. I don't see why you would need to have a separate residential program for people called "autistic" or "epileptic." They may have special needs, but that doesn't mean you have to establish a totally separate program.

We recently designed a model, 5-day-a-week residential program for children. Three of them are diagnosed "autistic." The particular environments that we developed for each of these three children were somewhat different than they would have been for deaf-blind children or retarded children, but the same system served all of them.

One point that I failed to make earlier is that I'm convinced you can serve everybody with the same service system but not

with the same service program. One residential system can handle everyone's needs because if you employ an individual placement approach you end up with different programs for each client. The notion that you would set up different service systems with different funding mechanisms goes counter to everything ENCOR and CASS are trying to work toward. I think you must do a good job of convincing parents that you are sensitive to their child's disability and that you're going to meet their specific needs.

Question: Have there been any tools devised that can measure how well persons who have been institutionalized have changed in their perception of themselves after moving to an integrated setting?

HITZING: There are very few, if any, data even on behavior change from institutions to community settings. I think everybody here who has experience with deinstitutionalization, however, has a gut-level feeling about the positive behavioral and attitudinal changes we see as clients become a part of the community. The data to answer your question are sorely needed.

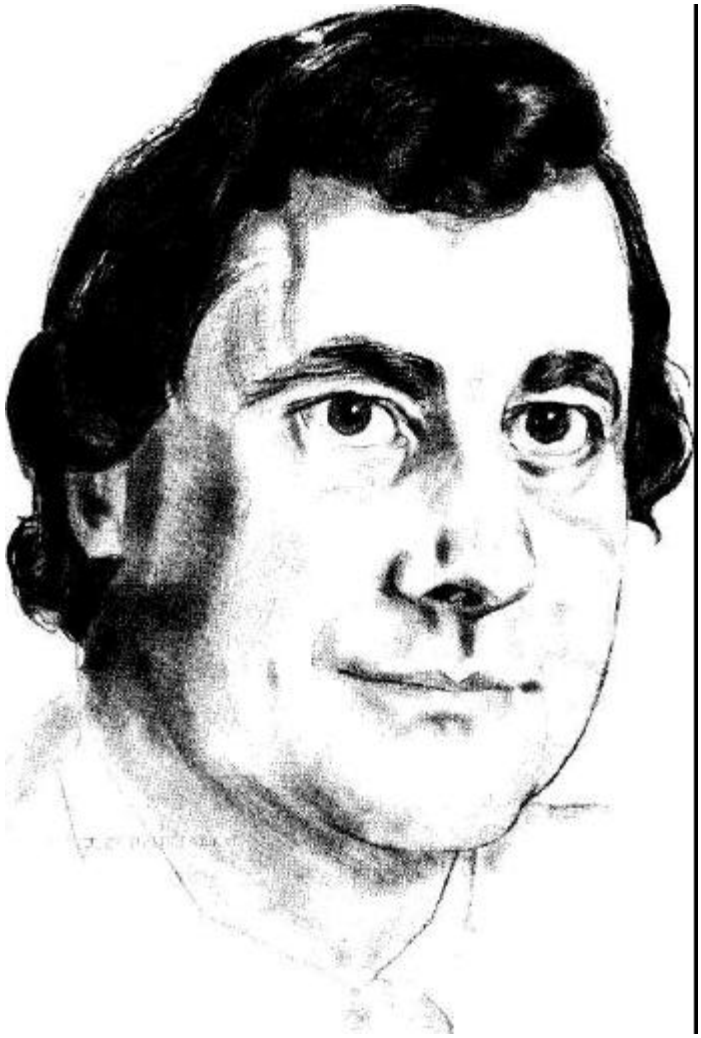
QUESTION: Has there been resistance to moving half a dozen handicapped people into one area?

HITZING: I think one prejudice we have when we hear somebody talk about really integrated settings, with emphasis on individual placements, is that such an approach is very radical. And we often equate being radical with being difficult to pull off. In truth, it's a lot easier to place people—logistically, financially, and every other way—in much more integrated settings. I once attended a symposium on normalization. The moderator of the symposium very angrily read an article from an Indianapolis newspaper, which said that a zoning board had voted down a 12-bed group home. She was incensed. She said, "It's 1977 and they're still prejudiced." But I had some sympathy with the zoning board. I personally don't want 12 people living across the street from me whether they are too tall, or too short, or on the same basketball team. I think we often create our own difficulties. My experience indicates that the public objects to the density of "handicapped" people imposed by non-integrated service systems, not to "handicapped" people per se.

REFERENCES

1. *Way To Go.* 1978. University Park Press, Baltimore.

THE PENNSYLVANIA SYSTEM



Mel Knowlton

the community service system that we are creating in Pennsylvania is not dramatically different from the models described for Macomb-Oakland and ENCOR. All three systems represent attempts to create normalizing social services for persons with special needs. Pennsylvania's client needs and its program models are very similar to those already outlined for Michigan and Nebraska.

I agree wholeheartedly with the overall service design concepts presented by Gerald Provencal and Wade Hitzing. In order not to be repetitive, I focus in this chapter on related considerations drawn from our experience in Pennsylvania, specifically: 1) the background of Pennsylvania's Community Service System, 2) the system's components, 3) Pennsylvania's efforts to create community-based, alternative living concepts for citizens with special needs, and 4) two major problems currently facing Pennsylvania's service system.

BACKGROUND

A massive movement was begun in 1972 by the Pennsylvania Association for Retarded Citizens to create less restrictive environments for Pennsylvania's mentally retarded citizens. The first funding breakthrough occurred in April, 1972, when the Pennsylvania Office of Mental Retardation received $1.9 million from the Pennsylvania General Assembly. We then had about 12,500 people living in institutions. Pennsylvania's public institutions now house approximately 8,000 clients. We have pushed to move institutionalized children back to their natural homes and to help institutionalized adults live independently. We have had 2,000 people move into one of these two options over the past 5V2 years and we are proud of this record.

We stress two factors in addressing the needs of our client population: deinstitutionalization and the prevention of institutionalization. We have maintained a policy for the past 4 years that 50% of all new community placements must come from an institution, with the remaining 50% from the community. We modified our policy this year so that now 80% must come from institutions and 20% from the community. We do have a waiver clause, however. If a particular county goes over its 20% allotment it does not have to send someone from the community into an institution for a week so that the person may receive a community space. Our percentage quotas are guidelines that we strongly encourage counties to follow. Exceptions are permitted.

Our primary residential priority in Pennsylvania is to identify and deliver services that permit clients to live at home. We support respite services, family training and education, homemaker services, in-home support services, transportation, leisure time activities, and recreational experiences. As a second priority we provide adoptive and foster home services. These settings receive the same ancillary services delivered to natural families. Our emphasis is on providing small, highly integrated living arrangements.

SYSTEMIC ORGANIZATION AND SERVICE DESIGN

Organization

Pennsylvania has an Office of Mental Retardation within its Department of Public Welfare. There are three bureaus under the

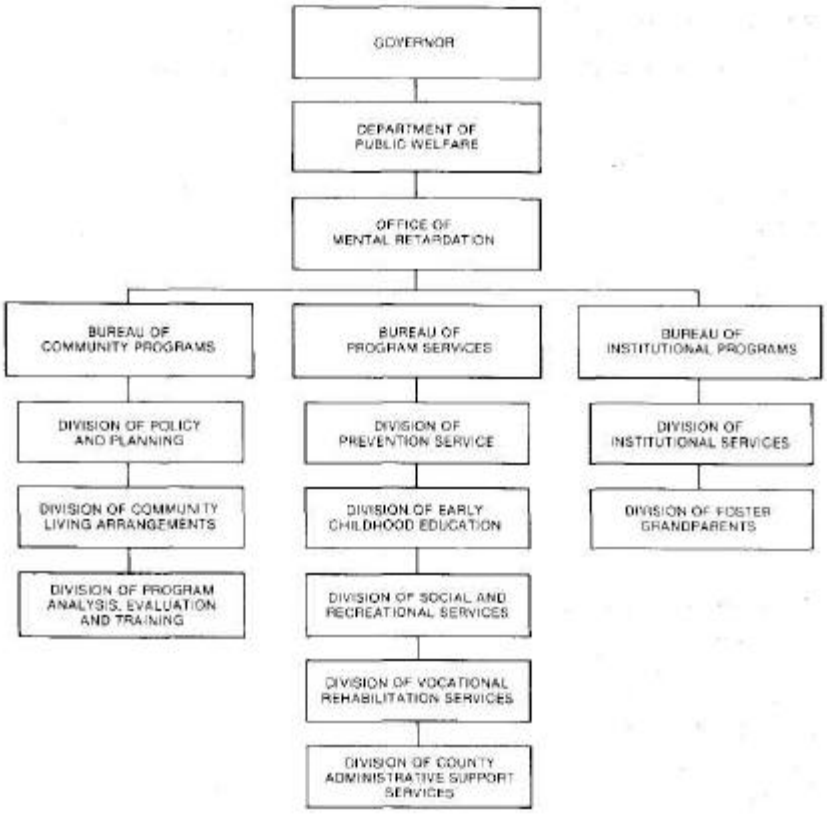


Figure 1. Organization of Pennsylvania's Office of Mental Retardation.

Office of Mental Retardation: 1) the Bureau of Community Programs, 2) the Bureau of Program Services, and 3) the Bureau of Institutional Programs. Community-based residential services are managed through the Bureau of Community Programs. Figure 1 depicts the overall organizational structure for the Office of Mental Retardation.

The various levels of authority and responsibility for Pennsylvania's mental retardation service delivery are shown in Figure 2. The Office of Mental Retardation is responsible for program standards, policy decisions, budgetary funding approval, evaluation, staff training, and program consultation. Additionally, Pennsylvania is divided into four regional, state-operated offices.

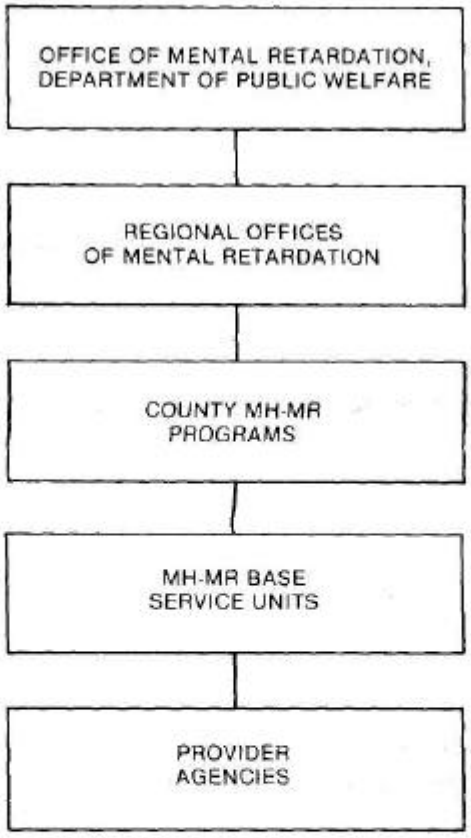


Figure 2. Levels of authority/responsibility for Pennsylvania's Service Delivery System.

Regional offices are responsible for program approval, monitoring program quality and outcomes, program evaluation, and staff training. The roles of the state office and its regional offices overlap and appear to necessitate frequent redefinition because of changes in policies and program standards.

The county level of Pennsylvania's complex human services design is responsible for the provision of mental health and mental retardation services. We have 41 mental health/mental retardation units for 67 counties, so some counties have joined together to form one unit. Local catchment areas, called Base Service Units, are charged with overseeing admission releases, active

treatment plans, case management, and diagnosis. Base Service Units may directly deliver services or may purchase services, such as community living arrangements, from provider agencies.

Monies are sent from the state to the counties. Most counties opt to contract with not-for-profit proprietors for services. In the area of community living arrangements we have only three providers who operate on profit-based accounting systems and five county units that directly operate programs. I might add that from our experience there is no difference in program cost or quality among not-for-profit, profit, and county-operated programs.

As the titles of its organizational units imply, Pennsylvania's service system is categorically organized. It exists specifically to meet the needs of people who are labeled ' 'mentally retarded." Clients who have secondary problems, such as sensory impairments, cerebral palsy, and emotional problems, may also receive services provided that their primary diagnosis is "mental retardation."

Service Options

Pennsylvania has developed a continuum of residential services that is flexible and structured to meet the needs of all mentally retarded individuals, no matter what the age or severity of handicap. The following list shows the services offered through Pennsylvania's Office of Mental Retardation. The first category, Family Resource Services, refers to the range of things we do to help natural families maintain their handicapped son or daughter at home. The degree to which these services are implemented is defined by county priorities and depends on the availability of funds.

Family Resource Services

- Visiting nurse services
- Family respite
- Family training and education
- Homemaker services
- In-home support
- Transportation
- Leisure time activities/recreation

Adoptive Home and Foster Home Services

- Visiting nurse services
- Family respite
- Family training and education

Homemaker services
In-home support
Transportation
Leisure time activities/recreation

If a child cannot stay with his or her natural family, we supply the same level of services to the child and his or her support system in the context of an adoptive or foster home. Some foster parents eventually adopt "mentally retarded" children. Initial foster placement provides the child and foster patents -with an opportunity to get acquainted before adoption.

Our Community Living Arrangement (CLA) Program is now in its sixth year. We initially designed this program like the ENCOR model but have since tailored it to meet the specific needs of our situation in Pennsylvania. All CLA staff members work for the service provider under contract with the county or director for the county. No foster parents are involved. All living settings are leased by the service provider.

Our service for individuals who are medically complex and multiply handicapped is known as the Developmental Maximation Unit. Three of these that are currently in operation house between 20 and 30 medically fragile individuals in skilled intermediate nursing home facilities. We are beginning to serve this group of clients in small homes and apartments with either nurses living in or on call to the regular live-in staff.

Another service that we offer, intensive habit shaping, is for children and adults with severe problems in areas like head hitting, eating, and toileting. It is a short-term program of behavioral correction. We attempt to offer these services in an apart-ment or home with only a single severely handicapped individual present and up to *two more clients who are not severely handi*-capped.

We serve most children from birth through 18 years old in our Child Development Program. The children typically have a wide range of medical and behavioral problems. Three out of four children reside in a house or apartment, with no more than one person demonstrating severe problems. We teach skills learned in normal living settings, such as toothbrushing, washing, and dressing.

The structured correctional program is for individuals who have problems with society. This is generally the juvenile or adult retarded offender who needs a short-term, structured, and in-

tensely supervised residential setting. These settings are usually small homes or apartments where a trained staff works with the retarded client to help facilitate his or her readjustment to society.

Most adults receive one of two interrelated services: adult training, delivered in a small group living arrangement; or adult minimal supervision, delivered in the context of the client's independent living setting. Adult training is offered in group homes or apartments with three or fewer clients. Emphasis is placed on teaching clients independent living skills. Clients may live in a group home and receive training and supervision for the rest of their lives, or they may move on to more independent living. The Adult Minimal Supervision Program is basically a service for people who only lack one or two skills for living completely independently, without any staff support. The skills most commonly taught are money handling, food preparation, and transportation skills.

Family Resource Services is another major program offered in Pennsylvania. The primary aim of this program is to offer a wide variety of support services to enable parents of "mentally retarded" children to keep their children at home. As noted earlier, Family Resource Services are available to adoptive parents, foster parents and to "mentally retarded" adults living independently in the community. These services are listed below:

Community Living Arrangement Services
- Developmental maximation unit
- Intensive habit shaping
- Structured correctional
- Child development
- Adult training
- Adult minimal supervision
- Family relief

Staff

The front-line staff members for our service programs must meet state civil service requirements, although they work for provider agencies or counties. Personnel are recruited through civil service bulletins, newspaper advertisements, and contacts with colleges. The starting salary for front-line staff members is approximately $6,500 per year, plus free room and board. Staff members are evaluated annually using a rating system. The typical ratio in the resi-

dential settings funded by our office is one staff member to three clients. This relatively high staffing ratio reduces staff pressure, prevents worker burn-out, promotes staff retention, and lessens operating and staff training costs.

Costs

The costs of our services depend on the particular needs of the client. We don't fix specific costs to identifiable disabilities. We set a general range of expenditure depending on the needs of individuals. The average cost per client for services provided through our system during the 1975-1976 fiscal year was $5,940. The costs for a particular client can fluctuate dramatically from year to year. For example, in settings with a live-in nurse the cost per resident may be $45.00 per day of state monies with approximately another $3.00 per day from Supplemental Security Income (SSI). Although this service is expensive, the average cost per day for institutional services in Pennsylvania is $70.00 per day per client.

The CLA program is totally funded through state dollars, with the exception of room and board payments supplied through SSI. Program funding is awarded to provider agencies in the form of annual cash grants, paid on a quarterly basis by counties. The first quarter payment is supplied at the beginning of the fiscal year. Subsequent payments are based on monthly bills submitted by provider agencies in relation to approved, line-item expenditures.

Comprehensiveness

One requirement for clients served through our office is that everyone must be involved in an appropriate day program or competitive employment unless they are too medically fragile to leave their living quarters or are elderly and do not wish to engage in work activity. For medically fragile children, public school teachers provide services in the home setting. The Department of Education supplies programming services during the day and the Department of Welfare provides similar services in the evenings and on weekends. Early education services, down to 2 years of age, are also available through either the Department of Education or the Department of Welfare.

Beginning in 1976, we have automatically paid 100% of the costs of vocational workshop training for clients entering CLA ser-

vices for 3 years. After the third year the State pays 90% and the county 10%. This policy has greatly expanded the availability of vocational services for clients and has assured an adequate supply of day program slots.

Our office also provides transportation services for physically handicapped people who live in rural areas. Funds are made available for the lease of a vehicle on an annual basis.

We attempt to stress the use of generic services whenever possible. We generally do not need specialized dental, medical, barber, or recreational services for persons labeled "mentally retarded." Instead, we need to utilize and support existing community services to promote the greater physical and social integration of our constituency.

LESSONS WE HAVE LEARNED

Sometimes we learn more from our mistakes than from those things we do correctly. This has certainly been our experience in attempting to develop normalized community services for Pennsylvania's citizens labeled "mentally retarded." The original continuum of community-based services that we created in Pennsylvania almost 6 years ago was patterned after the ENCOR service system. We have since made significant revisions in ENCOR'S design. Today we are basically administering two types of residential settings: those for children and those for adults. As noted earlier, we also provide a variety of ancillary services, such as medical and behavior shaping services, to meet individual clients' needs in these two general settings.

Smallness

We do not have a high proportion of clients served in group homes. We deemphasized the group home strategy early in our history. We started approximately 100 group homes and 50 apartments during our first couple of years of program development, but have only developed about 25 additional group homes during the last few years. We now primarily implement our programs in apartments or small homes housing up to three clients. Over 400 new apartment programs have been established during the past 3 years. Our group homes serve six to eight clients and our apartments serve three or fewer clients.

We believe that a smaller number of clients per setting has distinct advantages:

1. Clients are less likely to learn inappropriate behavior from one another when the number of handicapped residents is kept low.
2. The rate of staff burn-out is reduced with fewer clients per set ting.
3. Settings are less specialized, which reduces the need to bounce clients from one service setting to another to achieve less re strictive living arrangements.
4. Neighbors are less likely to oppose the establishment of a resi dential program when three or fewer clients are served.
5. Apartments are easier to locate and lease than larger dwell ings and are more likely to be located near transportation and shopping facilities.
6. Start-up periods are decreased for new programs because zon ing regulations are not affected and renovations are not gener ally needed.

As an example of how our thinking has changed relative to size, we initially established three Developmental Maximation Units for groups of 20 nonambulatory, medically complex people. These units were set up in wings of hospitals or nursing homes. Recognizing the poor quality of life experienced in such settings, we next moved to three-bed units. Today we are serving many medically fragile clients in single-client placement sites.

As another example, there was a period in our early years when we were putting higher functioning children into small group homes. Today we are capable of enabling most parents to keep their mildly disabled child at home through our Family Resource Services and other support systems. We have become very careful to support, and not needlessly supplant, clients' natural homes. Properly supported, family members represent a tremendous resource to children and adults with special needs.

Normalization

One of the major factors we tried to develop from the inception of our program was a strong commitment to normalization. We wanted to stress the importance of developing culturally acceptable behavior through using culturally appropriate intervention

strategies. One of the big problems we encountered very early, however, was that program staffs often become hyperactive about PASS and normalization. They thought that normalization meant you must program every minute of the client's life: Monday night was bowling, Tuesday night was ceramics, and so on. It simply drove clients crazy! We finally convinced the staffs that one aspect of good programming is leisure periods wherein clients are allowed to just sit back and take it easy. This was a very difficult lesson for many staff members to learn.

A key ingredient related to normalization, one that can be seen particularly in settings housing three or fewer clients, is the emotional bonding that takes place between clients and staff members. In smaller, more normative settings, staff members are able to lead more typical life-styles and to relate to clients in more effective and less artificial ways. Limiting the number of clients per setting results in more verbal interaction and touching between clients and staff members, which affords all parties a much more typical life-style than the one that exists in group homes or larger settings.

Start-up Help

As mentioned earlier, most counties purchase community services from nonprofit vendors. One of the problems that we have consistently faced is the need to encourage desirable people to establish and maintain placement sites. We now have prepared a cookbook from A to Z of the steps involved in establishing community residential services, called the *Implementation Packet: Community Living Arrangements Program for Citizens Who Are Mentally Retarded* (1). It includes our policies and regulations on community living arrangements; the roles and responsibilities of the state, regional offices, counties, and service providers; a model contract between a county and a service provider; a recommended budget system and budget standards; an application for project funding; a step-by-step procedure for developing community living arrangements in Pennsylvania; and reporting forms on vacancies, special incidents, fire reports. This is a government document. It can be mailed to you upon request at no charge.

We've also made the financial aspects of start-up much easier. A new service-providing agency getting off the ground in Pennsylvania does not need one penny, one residential setting, or one staff member. It simply fills out the application forms in our implementation packet, which are based on PASS and require an annual line-

item budget for specific services, such as developmental programming, transportation, leisure time activities, clothing, and food. If the agency's application is consistent with the priorities of its county's plan and sufficient monies exist in the county's budget, the program will immediately receive 25% of its first year's funding. In other words, if the program's yearly budget is $100,000, the provider agency will receive $25,000 as the first quarterly payment so that a director can be hired and the program can get off the ground. We currently experience very little difficulty in identifying providers and in initiating services.

Human services may be funded on the basis of program allotments or on the basis of a pre-set amount per client. There are liabilities associated with both program funding and per diem funding. Under program funding providers are sometimes slow to fill residential spaces because program monies still arrive when spaces are unoccupied. Additionally, program funding generally seems to necessitate a greater amount of paperwork. Under per diem funding providers are sometimes slow to move clients who are ready to live in less restrictive settings and are economically pressured to take an inappropriate client rather than risking a loss of funds associated with waiting for a more appropriate referral.

We have opted for program funding because: 1) it gets service providers' minds off the dollar on a day-to-day basis, 2) it gives providers a set budget for the whole year at the beginning of the year so they don't face bankruptcy if they are unable to keep beds filled, and 3) it facilitates directing provider attention to service quality versus service quantity. Whatever method is chosen, it is important to have a good system for fiscal accountability and monitoring.

Planning Ahead

One of the major problems we had in our first few years was a lack of fiscal comprehensiveness. We had all the money we needed for residential settings but failed to have sufficient fiscal coordination to support day programs for adults. Often, adult clients were left sitting at home during the last couple of months of each fiscal year because their day program money ran out. We finally corrected this problem. We now have a categorical amount that can be used for both living arrangements and day programs.

Our current fiscal planning format starts at the county level and works its way up from counties to regions to the state level. Plans are established for a 5-year time frame. The first year of any

plan is very realistic, and the other 4 years are projections to be modified on a yearly basis. We have recently experienced a $7 million budget increase, the largest single budget increase for new programs in Pennsylvania, largely due to data derived from our planning process. It is a beautiful sight to behold when planning works in this fashion. Not only did we get residential monies, we also received day program monies sufficient to develop comprehensive programs for all new clients.

Placement Stability

Our initial programs were highly specialized and required clients to move once they reached higher levels of independence. Now we are trying to stabilize clients' living situations by not moving clients around as much as we did with earlier strategies. We now move staff members and/or employ less specialized staff members who can continue with clients with temporary support from itinerant resource specialists.

Consumer Involvement

We are highly committed to parental participation and to direct consumer involvement. We supply PASS training sessions every other month in a different section of Pennsylvania that are attended by parents, primary consumers, and staff. One major factor that we push hard is client involvement in decision making regarding their lives. We are striving from a very early age to give children opportunities to make decisions. They learn to decide what to do when they can watch *Sesame Street,* play with a range of toys, or look at pictures in a book. Learning self-control is crucial for eventual independent living.

Parents and clients should be given every opportunity to be involved in making decisions regarding policies and activities of human service agencies. Just about every service-providing agency in Pennsylvania operates a client advisory group that makes recommendations to the board of directors and/or executive director. Professionals do not have all the answers. Programs work best when a partnership exists between service-providing staffs, parents, and clients.

Public Education

Public education is an essential feature of successful community program development. I have been involved in numerous zoning

hassles and have probably learned more about people labeled "mentally retarded" in such situations than any place else. For example, did you know that if a mentally retarded person walks on one square inch of your front lawn, your whole yard dies? Or that "mentally retarded" people can't cross streets or go up and down steps? These claims were actually made. They illustrate how far we have to go in revising public attitudes and beliefs toward people with special needs. This is an enormous issue. It challenges our ingenuity and cannot be overlooked.

Change Is Slow

It is my experience that we must be very patient and persistent in what we are trying to accomplish. Those committed to community services must sometimes wait for government bureaucrats and other societal leaders to finally fade away before significant progress can be achieved. It is hoped the people who replace them will have a better commitment to our constituency.

The intransigence of some leaders may on occasion be a blessing in disguise. Sound social service systems cannot be developed overnight. It takes time to build appropriate organizational structures, funding channels, policies, regulations, evaluation strategies, and service systems. It's not advisable to start out with the clients who are the most complex problems because they offer the greatest chance for failure. Initial success is of utmost importance. Community agencies that have never provided developmental services cannot give first-rate services overnight. You must take time to give new agencies support, direction, and experience before moving to highly difficult clients. You must take time to give the emerging system every opportunity to succeed.

When you're dealing with a population of 12 million people, as we are in Pennsylvania, you do not develop a sound community-based service system in 5 years. It obviously takes a lot longer. We have worked very hard to develop a firm undergirding for the community service system needed in Pennsylvania. We have kept our programs flexible during their emergence and as a consequence we have adopted better ways of doing some things. Most of these better ways, incidentally, have come from service providers, not from state government. If you wait for state government to identify needed service innovations, you are likely to be in big trouble. Open communication between community service providers and state government leaders is essential for constructive service advancement.

Staff Training

It is really a tough job, in my estimation, day in and day out, to work with people who demonstrate special needs. It is imperative that we strive to keep staff skill levels high and to minimize the pressures that workers face. Staff members need training, plenty of free time, and a normative life-style. The smaller living units that we are now providing have produced a notable improvement in staff morale.

Many community service providers are people committed to helping clients change in socially desirable ways. They find it very rewarding to see clients develop independence and productivity. We must support community service agents by teaching them efficient procedures for helping clients grow and develop. We must modify rate structures to provide incentives to service providers for client advancement.

Pennsylvania provides two basic types of training for front line staffs: PASS and Project Main, PASS training sensitizes staff members to the principle of normalization. Project Main increases staff skills in the areas of individual assessment and programming. We are also engaged in developing a staff training model in conjunction with certain colleges. We are concerned with establishing a manpower development model and career ladder similar to that existing in Canada. We need to train new staff members and to retrain institutional staff members to enter community programs. We are investigating certification programs based on 2-year degrees and 4-year degrees, backed by increases in salaries and other benefits. We are on the right track but much remains to be accomplished in this area.

Accountability

We clearly must show that clients derive benefits from our services. Our state legislature investigated our community living arrangement program 2 years ago. They indicated that we must demonstrate benefits to clients before we could expect substantial increases in program monies. We are presently engaged in a large-scale effort to do just that. We are rigorously evaluating the developmental growth of clients whose instructors receive intensive levels of staff development training. The initial data from this project are very favorable. I suspect that the tentative outcomes of this project were a major factor leading to the large budget increase that our bureau received this year.

We push for accountability in three different areas: program quality as measured by PASS, fiscal accountability as assessed through our specially designed fiscal audit system, and client outcome accountability as evaluated through individual assessments. We are concerned with generating maximum client growth in normalized settings for an economical cost.

MAJOR PROBLEMS

Our two biggest problems are in the areas of: 1) manpower development and 2) neighborhood oversaturation. Manpower development is becoming particularly critical because of the shift that is occurring in the types of clients we are serving. During the first few years most of the client population we dealt with exhibited moderate to mild disabilities. We are now to the point that most people left in our public institutions are classified as severely or profoundly retarded. Most have serious medical and/or behavioral problems. Aside from individuals who are leaving their homes in the community, almost all of our future work will center on a highly dependent group of persons. This situation creates great demands for staff training. Curricular materials and programming strategies simply do not exist in many cases.

The issue of neighborhood oversaturation has become vexing. We work very hard to control the distances between our service settings, but we have no control over other agencies serving different special needs groups, such as juvenile corrections. The sheer number of consumers served by social welfare agencies and the limited availability of affordable housing intensify this problem. We hope to overcome this problem through increased interagency communication.

QUESTIONS AND ANSWERS

QUESTION: What kind of feedback do you get from clients when you ask them to move from one setting to another?

KNOWLTON: We sometimes have people who do not want to move. I think there are always going to be some people who say, "Hey, I'm in an institution, I've been here 20 years and I don't want to leave." And there are others in community settings who will not want to move. With the approach we're adopting now, they don't have to move; we move staff members.

When you're talking about publicly funded living settings, it's pretty difficult to justify purchasing intensive structure and supervision for the person who no longer needs it. We must balance the desires of the client and the cost to society of satisfying his or her desires. One of the things we have to watch out for is that we operate at the economic level of the client. I've seen many group homes that were so plush, with a color TV as big as a movie screen, and things that clients will never afford at their potential earning level. We must maintain attention to conserving society's social welfare expenditures while providing high quality environments for clients.

QUESTION: HOW close are you on age mixing? What are your criteria for grouping people by chronological age?

KNOWLTON: For children, we have a fairly wide range. One home may have one person who is 1 year old, one who is 7, and another who is 16. We want people to see that a child moves out on his or her own after reaching a certain age. It's anticipated that when you become an adult you move away from the home setting and develop one of your own. In adult settings, we may have an age range of 18 through 30 in one setting and 30 through about 45 or 50 in another. Some individuals may fit more properly into a higher or lower age range, depending on their personality and how they get along with other people.

QUESTION: DO you provide community alternatives for everyone? That is, can you meet every individual's needs?

KNOWLTON: One of the things we try to do, but are not always successful in doing, is to provide living settings that will meet everybody's needs. I frankly don't think it's possible to meet everybody's needs. To begin with, clients very rarely know each other when they move into a program. Moreover, even when they go in as friends, they may end up as enemies after living with each other.

Many people are concerned that clients should have the right to choose, but the choices they have are so poor and their need for security is so deep. Those of us who are responsible for service development and quality of life must create a range of choices. We cannot wait! We must create apartments, train staffs, and build good programs before clients have to make unjust choices. I agree that people should have involvement in decision making about where they live. But clients' choices have little meaning in the absence of reasonable alternatives. We must offer a flexible array of service options.

REFERENCE

1. *Implementation Packet: Community Living Arrangements Program for Citizens Who Are Mentally Retarded.* 1977. Office of Mental Retardation, Department of Public Welfare, Commonwealth of Pennsylvania, Harrisburg.