

TESTIMONY  
ON  
COMMUNITY AND FAMILY LIVING AMENDMENTS  
OF 1983

by  
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Minneapolis, Minnesota

## Community And Family Living Amendments Of 1983

Chairman Durenburger and Senator Chaffee, it is with a great deal of pleasure that I come here today to testify in firm support of S. 2053.

My name is Lyn Rucker, I am the Executive Director of Region V Mental Retardation Services in Lincoln, Nebraska. Region V provides community based day, residential and support services to over 550 persons with mental retardation in the sixteen counties of Southeast Nebraska. Of those individuals, 139 have severe or profound mental retardation and 102 are classified as being "high need" due to physical, medical and/or behavioral characteristics. We serve 297 persons residentially, and nearly all live in a home of five or fewer people. There are only two exceptions in Region V; one house has six persons and one seven. All of the individuals we serve in day programs are involved outside of their homes in locations such as work stations in industry, supported employment, competitive employment or Region V industrial sites.

Region V has been actively involved in deinstitutionalization for over fourteen years. We believe that all persons, regardless of the severity of their handicapping condition, will ultimately live in complex, heterogeneous integrated community settings. Therefore, our policies prohibit any entrance criteria, other than the diagnosis of mental retardation. We are involved in integrating individuals with all levels of need into towns with populations of from 200 to 200,000. Fifteen of our sixteen counties are rural.

In 1969 there were 2200 persons with mental retardation confined to the one mental retardation institution in Nebraska. Today there are still 460.

Through the 60's and early 70's opponents to deinstitutionalization maintained that persons with severe/profound mental retardation could not be moved to the community -- but they have been moved to communities in Nebraska.

Then it was said that persons with behavioral disorders associated with mental retardation could not successfully be served in the community - but they were and are in Nebraska.

Then it was maintained that mentally retarded persons with serious medical needs required institutional care forever - but persons with such needs are now living successfully in the rural and urban communities of Nebraska.

Since the community placement of all persons, regardless of the level of handicapping condition has happened, is happening, and should continue to happen, the financial security implicit in S. 2053 must be accorded to retarded citizens living in community facilities throughout this Nation.

The great advances realized in integrating citizens with mental retardation into rural and urban areas of this country during the past twenty years must not be forfeited. Inadequate funding for community programs threatens just such a setback. Yet, outmoded, segregated, institutional models of care continue to enjoy almost unlimited federal funding. The Community and Family Living Amendments thus are designed quite properly to change that anachronism. I stand in full support of that change.

Fifteen years of providing community services to persons with mental retardation in Nebraska provides eloquent support for Medicaide restructuring. The Nebraska experience has taught us that:

Persons With All Levels Of Retardation Thrive In The Community

Services Are Effectively Monitored

Service Costs Are Significantly Less In The Community

Systems Can Be Organized In Both Rural And Urban Areas

## I. Persons With ALL Levels Of Retardation Thrive In The Community

I want to reiterate that community programs no longer need to justify their existence nor defend their worth. Quite the opposite is true. Since we know that people with complex disabilities can be well served in community settings, we must ask why the violent solution of institutionalization is ever justified.

I raise this issue because some opponents of S. 2053 cite studies which indicate that persons with severe disabilities "do better" or "are happier" in isolated, segregated settings. Those of us who work in community programs may be faulted for letting this type of research go unchallenged. The difficulty is that most community programs are not research oriented. Our time and our money is aimed at directly serving people with mental retardation. Further, many community programs are similar to Region V in terms of research policies. We set high standards for any research conducted in our programs. The privacy and dignity of persons with mental retardation must be respected. We will not condone research practices which violate that privacy and dignity.

Therefore, it was with great satisfaction that we reviewed the results of a recent study which honored our research requirements. The study, published in the Spring, 1984 Journal of the Association for Persons with Severe Handicaps, compared data on certain persons served in our program with counterparts served in an institutional setting. Titled "Changes in Labels of Mental Retardation: A Comparison of Institutional and Community Programs", the study stated,

"... the common wisdom that persons with severe and profound mental retardation should be served in large congregate settings is called into question. In fact, it might be argued that greater needs dictate smaller settings in which effective training, environmental stimulation, and life-style management can be ensured."

I would like to submit this study as part of the record today.

The above cited study absolutely confirms what experience has taught us, namely, that the more handicapped the individual, the smaller the living

living environment must be. We stand firm in our position that people with all levels and types of disabilities should be served in community settings. If we commit ourselves to this approach, we can avoid wasting time and resources in trying to prove or disprove the efficacy of what is, I repeat, a violent response to the presence of a disability: institutionalization.

Because S. 2053 is ultimately about individual lives, I want to close this section with a vignette about a real person. I will call him David, although that is not his real name.

David entered a community program in Region V in 1982, after thirty-eight years of institutionalization. He was labeled as having severe mental retardation and like so many persons who leave the institution, he took medication for a "behavior disorder". He was considered a "major behavior problem." Staff in our agency were cautioned by the institutional staff to expect aggressive and frequent behavioral outbursts.

Today, less than two years later, David no longer takes medication for a behavior disorder. He is highly regarded by all persons with whom he works. His initiative and follow-through are superb. He likes to work. He occasionally displays temper, but he is not regarded as a person with a behavior problem, by any means.

The director of the program in which David is served, David Merrill, Region V-Fairbury, was asked to identify the variable(s) which he believed made a difference in David's life. Merrill said, "I remember the first week he was here. I dropped by his house after work one day and David was relaxing with a cup of coffee. It was apparent that he loved having the opportunity to make choices. It was like, 'I'm coming home to my own house. I can unwind in my own way' It

seems so ordinary. But it appears to be the key. Just the environment. Just the expectation that he could make choices."

I ask you to look beyond labels when you consider S. 2053. Look at David, and the thousands like him, who do not deserve institutionalization simply because it appeared to be a good idea a hundred years ago. I urge you to give S. 2053 your full support.

## II. Services Are Effectively Monitored

The key word here is "effectively". Community programs, we have learned, possess the capacity to combine traditional and non-traditional monitoring systems in a way that multiplies safeguards to the system and for persons with mental retardation.

Traditional service monitoring includes such procedures as accreditation and licensure. Region V is accredited by the Accreditation Council for Services for Mentally Retarded and other Developmentally Disabled People (AC MRDD). A Region V agency was, in fact, the first community program to be so accredited. While AC MRDD accreditation is voluntary on our part, we believe that programs serving persons with mental retardation should be monitored by external agencies. We are pleased that this concept of external review is a part of S. 2053.

Licensure is another traditional procedure which safeguards service quality. In Region V, all residential facilities operated by the Region, of which there are 45, are licensed.

The point is not that Region V has uniquely achieved accreditation and licensure. Rather, the point is that the traditional controls of accreditation and licensure are in place and are available to monitor community programs everywhere. In other words, the same mechanisms which the better universities and hospitals have always relied upon to assure service quality are equally available in the community.

But community programs have something else. The non-traditional, or more precisely, the natural system of community vigilance is available only in the community. The isolated, insular institution, with its physical, psychological, and spiritual separation from everyday community life cannot avail itself of families, friends, neighbors, and professionals who interact every day with persons who receive our services. In Region V, we receive this feedback daily from people who owe us nothing, and we have come to expect constructive criticism concerning the effectiveness and humaneness of our services.

Even the most mundane areas of the service are critiqued by this method. For example, a parent drops by a group home unannounced near supper time. This parent wonders about the menu. It seems somewhat high in calories. The next day we get a telephone call. "How are menus planned?", we are asked. "Who reviews them? How are special diets prepared? Are individual likes and dislikes taken into account?" We explain that menus are prepared in advance and reviewed by a nutritionist, that our staff assist with all kinds of special diets, and that individual preferences for food are taken into account. We also follow up on the parent's concern. If there is ever a problem, we need to know about it.

Or consider a recent incident in one of our small town programs. A neighbor of a typical four-person group home contacted the agency. She had become acquainted with the women living next door to her. She was also somewhat acquainted with the staff. She became troubled by one such staff person. She said that she had not observed the same type of family-like interaction between this staff person and the women living there as she had observed between other staff and the women. Specifically, she observed a staff person raising her voice to one of the women. While this may sound trivial, the point is that this was quickly exposed and dealt with before it could develop into anything more serious. It has been my experience that such inappropriate staff behavior is not caught

in institutions until it develops into a major incident, in some cases threatening the health and safety of the persons served.

It should be apparent that I am not presenting Region V or any community system as immune to the carelessness and even the abuse which has characterized the institutional treatment of persons with mental retardation far too much. What I am saying, with total conviction, is that the best monitoring system we know of, the best safeguard anywhere, is public scrutiny. Again, I emphasize that this is uniquely available to community programs. That is, institutions, by their *very* nature are isolated from such scrutiny.

I have noted that traditional and natural monitoring systems are available to community programs. I want to highlight an additional procedure we use in Region V. This is our own internal quality audit, which we call Systems Review. Each year we involve staff, volunteers, and outside experts in a thorough review of Region V's services. Systems Review is designed to be the most demanding of all formal review procedures. We believe that if we are self-critical and that if we consistently strive to improve services, we will be in a much stronger position to welcome all other evaluations.

Another very critical external monitoring system built into the Region V system is the Program Ethics Committee. This regional committee meets monthly to review restrictive procedures approved by the local agencies' Behavior Management Corps Teams. Membership on this committee is diverse. The current committee has an attorney, a psychiatrist, two psychologists, two parents, a clergyman, a representative from People First of Nebraska, a program specialist from another agency, and a public policy specialist. This committee provides independent oversight on all questions involving restrictions and psychotropic medications.

This brief sketch of monitoring systems available to community programs is by no means comprehensive. I have not discussed, for example, Region V's Client Advisory Committee made up of consumer representatives from each Region V agency.

I have not explained how the human scale of community programs works as a safeguard for persons who receive services.

In the final analysis, our particular monitoring system is not the issue. Our system is simply an example of the depth and breadth of monitoring systems available in community settings. It is a solid piece of evidence that our best instincts (our instincts which tell us to accept persons with disabilities and to bring them into our lives) can translate into workable and accountable service delivery systems.

### **III. Service Costs Are Significantly Less In The Community**

Costs of providing services (even for the most severely handicapped) are less in community programs than institutions in Nebraska. In a study conducted by Touche Ross & Co., comparing the two models in Nebraska, the findings included an analysis which demonstrated that not only are current costs per client less in the community, but the costs may be reduced even further in the community as clients achieve community living skills. "As institutional behaviors are eliminated and community/residential living skills are learned, the cost of serving the (institutional) placed client should be reduced."

The average annual cost for an individual receiving a full range of day and residential services (including transportation, Social Services, and Administration) in Region V is \$20,193. The average cost in the mental retardation institution is \$38,008 and the costs in the MR/MH units of the Regional Center (psychiatric hospital with limited facilities for mentally retarded persons with psychiatric problems) exceeds \$50,000 per individual. Even if we were to single out one of the Region's most expensive programs (the agency at Fairbury for high

1 Cost Study of the Community Based Mental Retardation Regions and the Beatrice State Developmental Center, p. 54, (August 15, 1980).

need persons), the cost per client, \$26,332, is still significantly lower than institutional costs.

There are several reasons for the tremendous cost of service differences between institutions and communities:

Institutions have a high proportion of relatively inflexible overhead costs (for example, building maintenance, grounds, utilities, medical services, and administration). As institutional populations go down, the costs per person go up because of the inelastic nature of such institutional costs. In my experience, this factor alone provides a strong motivation for institutional staff and state officials to unjustifiably keep beds full and capacity up.

Community programs utilize small homes with the "family" (clients and staff) participating in routine cooking, cleaning and home care. As an active participant in that family unit, clients develop residential living skills. Institutions, on the other hand, employ or contract for food service and custodial workers in addition to direct care staff. Skills are not gained by the consumer and costs go up. Moreover, because of the large numbers involved, even if clients were expected to perform such services in the institution, the experience would be one more akin to that of a basic trainee as he spends his first weeks in military service than to normal family living skills.

Community programs integrate high need clients into homes serving predominately moderate need clients without increasing staff. This approach provides for appropriate peer modeling (i.e., clients watch other higher functioning persons and emulate their behavior), blending within the community, and a lower cost.

Community programs have the flexibility to recognize the client's

independent living skills. As a result, the community has the opportunity to serve a blend of low, moderate and high need individuals in less costly programs. This is not true in most institutions. In institutions, because of the large numbers involved, you get the same full range of care whether you are low or high need. Individuality of service, training and costs is lost in the institutional model.

#### **IV. Systems Can Be Organized In Both Rural And Urban Areas**

The state of Nebraska is divided into six geographical regions for purposes of providing services to mentally retarded citizens. Each of the six mental retardation regions serves persons with severe/profound mental, behavioral and medical needs. Four of the regions consist entirely of rural areas, one (Omaha) consists primarily of urban areas, and one (Region V) has both rural and urban (Lincoln) areas. For persons interested in greater detail on the development of rural programs for persons with high needs, I have provided a paper I prepared for presentation to the Association for Retarded Citizens-Executives Training at National Convention, regarding that topic.

For the purposes of this hearing, suffice it to say that the provision of services to persons with severe/profound mental, behavioral or medical needs in rural communities is not uniquely difficult, but depends to a great extent on one of the traditional strengths of community services - sharing resources.

The foundation principles of placing decision making as close to the individual as possible, regularly involving consumers and consumer representatives, seeking and responding to community vigilance, and maintaining contacts with medical and professional support personnel are just a few of the fundamental components of a quality community program, regardless of the functioning level of the persons served.

Likewise, when hiring staff, characteristics that are valuable in staff

working with any group of persons with mental retardation are sought: experience, attitude/philosophy and creativity.

Judgments regarding S.2053, its passage and amendments should be based on the premise that persons with all levels of mental, physical, behavioral and medical needs are being successfully served in the community. The only limitations to serving everyone in a community setting is the money with which to do it. S. 2053 would substantially eliminate that barrier.

## **V. Summary**

This is 1984. The technology to serve all persons in the community regardless of their handicapping condition exists today. S. 2053 offers clients, parents and professionals the opportunity to unite and focus our energies on the further development of quality integrated community systems designed to serve all persons with disabilities.

I urge you to continue to lead this march to the future. I urge you to focus your numerous resources on making this bill as strong and as supportive of people developing independence as you can. Using your leadership as a model, perhaps the "mental retardation community" can remember that we are here for the same thing: the growth and development of individuals.

I wish to give grateful recognition to Mary Jane Humphrey, Director of Planning and Policy Analysis, Region V, for her assistance in the preparation of this submission.

# Changes in Levels of Mental Retardation: A Comparison of Institutional and Community Populations<sup>1,2</sup>

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## Article Descriptors

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*Increasingly, persons with complex disabilities are served in community settings, and institutionalization is less often a treatment of choice. However, relatively little work has been reported comparing the community and institution in terms of individual data. This study was conducted in order to compare changes in level of mental retardation among persons served in a community-based service system and institutionalized persons from the same geographic region. Comparisons were made at all levels of mental retardation and of cohort groups matched on age, sex, ambulation, and initial level of retardation. In general, persons in the community were more likely to increase their functioning level, while those at the institution were found to decrease at a higher rate. Particularly noteworthy differences were found within the severely retarded group. The impact of community interaction and stimulation is discussed, and implications for service providers are suggested.*

In recent years, the right of mentally retarded citizens to participate in society has been increasingly recognized, and institutionalization has become a less frequent occurrence in the United States (President's Committee on Mental Retardation, 1976). Community participation has been enhanced by a variety of educational, residential, vocational, and family services as well as by specialized supports and resources (PCMR, 1979). Although the conventional wisdom has held that certain persons—especially those presenting difficult training, medical, or management

challenges—should be served in congregate facilities, it has been shown that community-based programs may serve a population equally complex as that found in institutions (Menolascino, McGee, & Casey, 1982).

In 1974, the President's Committee on Mental Retardation expressed a belief in the ability of persons with mental retardation to continue to grow and develop, if they were provided environments offering the rights and opportunities afforded other citizens. This is a perspective that is often asserted and generally supported by philosophic and legal arguments. Data evaluating the community experience are less often reported, and comparative data on individual persons experiencing community and/or institutional lives are even less common. Nevertheless, a few studies suggest areas of interest for potential investigation. Aames and Moen (1976), for example, reported adaptive behavior changes in residents of community group homes; Silverstein (1969) investigated the longitudinal decline in IQ of persons residing in a large institution; Phillips and Balthazar (1979) documented declines in communication during prolonged institutionalization; and Schalock, Gadwood, and Perry (in press) analyzed differential effects of community residential settings.

The present study was conducted in order to compare changes in level of mental retardation, according to standards of the American Association of Mental Deficiency (AAMD) (Grossman, 1973) between persons served in a state institution and those served in a community-based service system.

## Method

### Programs Studied

The community-based mental retardation (CBMR) services are provided by a 16-county regional agency with seven area programs serving a total client population of 540. These individuals live in a variety of small residential settings, the largest serving seven persons, dispersed throughout the communities. Individuals under age 21 receive vocational services provided by each area program, and generic community services are used for meeting most medical, psychological, and recreational needs.

The institution is a state-operated facility serving 480 individuals with mental retardation. Approximately 30% of the institution's population is from the same 16 counties served by the CBMR. Residential services are provided in cottages serving 16 people or in large dormitory-type buildings. The institution provides for its residents a variety of educational and vocational training programs. Almost all medical, psychological, and recreational services are available at the institution.

Both the institution and community-based program are serving individuals of all ages, abilities, and needs. Both are accredited by national organizations and are monitored by the same state regulatory agencies.

### Subject Selection

Existing records from their respective programs (community or institutional) were reviewed for all individuals from the 16-county region. Only those with standardized measures of intelligence and/or adaptive behavior ratings that could be classified by functioning levels based on AAMD standards were considered eligible for inclusion in the study. Assessments and classifications at the institution were typically completed by members of the facility's psychology staff; those in the community were generally done by licensed private practitioners or community mental health center psychologists.

Of those persons meeting the assessment criteria, those who had an AAMD classification on record during or after 1976 and who had a subsequent classification assigned after at least three years in the same program, were chosen for the study sample. This procedure produced a sample of 344 individuals with two classifications at least three years apart. The earlier classification was considered the *initial* classification, and the most recent was termed *current*. Of the sample, 198 persons were in the CBMR and 146 in the institution. Analysis of the initial classifications of those in the CBMR showed the following: 58 individuals classified as mildly retarded; 75 as moderately retarded; 31 severely retarded; and 8 profoundly retarded. The remaining 26 persons were nonretarded or in midrange (e.g., moderate-to-mild). Analysis of classifications for those from the institution showed 2 individuals classified as mildly retarded; 11 moderately

retarded; 51 severely retarded; and 79 as profoundly retarded; with 3 individuals being nonretarded or in a midrange. Initial classifications for subjects were compared to their current classifications in four different ways.

### Comparison 1

**Procedure.** The first comparison was made between all subjects, institutionalized and community-based, who met the selection criteria described above. Of the 198 persons in the community and 146 residing at the institution, the number whose functioning level had increased, decreased, or remained the same (according to AAMD criteria) was computed. These figures were compared and analyzed in order to ascertain any differences in changes in levels for the entire sample in the two types of programs.

**Results.** Changes in AAMD classification for all subjects are summarized in Table I. The tendency for individuals in the community to increase in functioning level was greater than that of persons in the institution, where a greater relative frequency of decreased functioning levels was observed. These differences were found to be statistically significant when subjected to the Chi-Square test of significance ( $X^2 = 31.39$ ;  $df = 2$ ;  $p < .001$ ). (Note: in only two cases were changes in classification found to be greater than one level.)

### Comparison 2

**Procedure.** Of the 344 individuals in Comparison 1, 109 were classified as profoundly retarded (87) or nonretarded (22). These subgroups could vary in only one direction with respect to functioning level (the profound group upward, the nonretarded group downward). In recognition of this fact, Comparison 2 was conducted to compare changes in functioning level between the community and institution groups with the profound and nonretarded subgroups omitted from analysis. This resulted in an analysis of changes in level of mental retardation of 65 persons at the institution and 170 persons in the community.

**Results.** Changes in functioning level for these groups appear in Table I. As in Comparison 1, the percentage of individuals increasing in functioning level was greater in the community, with the number decreasing being higher at the institution. These differences were found to be statistically significant ( $X^2 = 62.5$ ;  $df = 2$ ;  $p < .001$ ).

### Comparison 3

**Procedure.** Two subgroups (the moderately and severely retarded) contained a sufficiently large number of persons to allow statistical analysis of changes in functioning level by subgroups. Of the 86 persons with moderate retardation in the study, 75 resided in the community, and 11 were at the institution. Within the severe subgroup, 31 were in the community and 51 at the institution. Changes from the initial classificatory

**Table 1**  
**Changes in AAMD Classification**

	N	Mean Age	Increased	Decreased	No Change
<b>Comparison 1—All Subjects</b>					
Institution	146	34.7	11( 7.5%)	36(24.7%)	99(67.8%)
Community	198	40.4	59(29.8%)	21(10.6%)	118(59.6%)
<b>Comparison 2—Excluding Profound &amp; Non-retarded</b>					
Institution	65	36.6	8(12.3%)	35(53.8%)	22(33.8%)
Community	170	33.1	58(34.1%)	13( 7.6%)	99(58.2%)
<b>Comparison 3</b>					
<b>Moderately Retarded</b>					
Institution	11	34.7	3(27.3%)	2(18.2%)	6(54.5%)
Community	75	31.4	23(30.7%)	4( 5.3%)	48(64.0%)
<b>Severely Retarded</b>					
Institution	51	36.2	4( 7.8%)	32(62.8%)	15(29.4%)
Community	31	28.9	22(71.0%)	1( 3.2%)	8(25.8%)
<b>Comparison 4—Cohort Study</b>					
Institution	21	27.6	3(14.3%)	6(28.6%)	12(57.1%)
Community	21	27.2	10(47.6%)	0( 0.0%)	11(52.4%)

levels were compared for both groups, and differences between institution and community were analyzed.

**Results.** Analysis of changes in functioning levels for the moderately retarded subgroup (Table I) showed no significant difference between institution and community. The percentage of persons with increasing levels of functioning, however, was greater in the community. There was a correspondingly greater percentage decreasing in functioning level at the institution ( $X^2 = 2.43$ ;  $df = 2$ ; N.S.).

When functioning level changes between institution and community were studied for the severely retarded subgroup, significant differences were found. Persons in the community were much more likely to increase their functioning level, while those at the institution were found to decrease at a much higher rate ( $X^2 = 41.38$ ;  $df = 2$ ;  $p < .001$ ).

Finally, although the mildly retarded and profoundly retarded subgroups were not subjected to statistical analysis (due to sample size), it was noted that the differences were consistent with those observed for the other groups. Within the profound subgroup, the percentages increasing in functioning level were 3.8% at the institution and 25% in the community, with the remainder showing no change. In the mild subgroup, 50% decreased at the institution and 50% remained the same, while 12.1% decreased, and 75.9% remained the same in the community.

#### Comparison 4

**Procedure.** Although both the community and institutional programs served persons with all levels of disability and a wide range of ages, it was considered important to conduct a cohort study that would match individuals served in the community with those served in the institution. Accordingly, a sample of 42 persons was selected, constituting 21 matched pairs. These individuals were matched on the basis of age, sex, ambulation, and initial level of mental retardation (14 in each the moderate, severe, and profound levels). A blind matching process was employed to ensure that outcome measures were not available to raters. The pairs ranged in age from 10 to 48 years, with 8 pairs being female and 13 male. Four pairs were nonambulatory. Following the matching process, changes in level of mental retardation for the community and institutional groups were compared and analyzed.

**Results.** A summary of changes in functioning level for the cohort study appears in Table [ . It can be seen that the tendency toward increased functioning levels in the community is repeated here: the observed differences were found to be statistically significant

#### Discussion

In the programs studied here, the trend toward increased functioning levels in the community is clear.

$X^2 = 9.81$ ;  $df = 2$ ;  $p < .01$

Although the concept of functioning level *per se* is not a precise measure of individual skills and behavior, it is widely accepted as one significant indicator of general developmental status.

The institution studied here has strong capabilities in staff development and programming, maintaining a sophisticated system of daily training and data collection. Therefore, it does not seem likely that deficits in this area can account for the differences found in this study. Thus, even though the institution might become the enriched environment argued for in *Wyatt v. Ireland* (1978), the effects of institutionalization may nevertheless be detrimental.

Viteilo, Atthowe, and Cadwell (1983) found that placement from institutions is dependent upon higher levels of cognitive and adaptive functioning. If, as Throne (1977) asserted, intelligence can be increased through training, it might seem reasonable to expect an effective institutional training program to prepare persons for community placement. The data reported here suggest a basic fallacy in this line of reasoning, indicating, instead, the likelihood of a decline in functioning level over time in the institution. This observation is consistent with findings of significant skill losses among institutional residents (Keith & Lange, 1974). On the other hand, when competent programming is combined with community experience, Throne's (1977) expectations seem to be borne out.

The findings of this study, when considered in the context of the broader movement toward delivery of services in homes and homelike settings, suggest

several implications for service providers. First, the common wisdom that persons with severe and profound mental retardation should be served in large congregate settings is called into question. In fact, it might be argued that greater needs should dictate *smaller* settings in which effective training, environmental stimulation, and life-style management can be ensured. Second, it would seem reasonable to conclude that environments that are more nearly normalizing can also be effective, if the proper programming components are present. Although it is possible for normalizing environments to preclude effective training (Throne, 1975; Keith, 1979), those studied in the present investigation combined community access and successful programming. A centralized, congregate facility is not necessary to attain this end. Third, the goal of keeping virtually *all* members of future generations in their home communities is not only possible, but is also likely to be effective in enhancing their intellectual and social capabilities, if local programs are properly arrayed.

Over the past two decades, many arguments have been advanced on behalf of community alternatives to institutional programs. Generally, the burden of proof seems to have been on the community to prove its role in the lives of individuals. It becomes increasingly clear that home and community are capable of assuming natural, effective roles for persons with mental retardation, and that the well-worn reasons for disrupting these roles are no longer compelling.

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## Footnotes

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LIFE IS JUST WHAT YOU MAKE IT

OR

A Difference You Can See: One Example of Services to Persons  
with Severe or Profound Mental Retardation in the Community

PURPOSE

The purpose of this paper is to describe how one rural Nebraska community based program for persons with severe/profound mental retardation was established, why it was designed the way it was and what we have learned from that experience. The following topics will be reviewed:

- \* General background information will be given to familiarize the reader with the structure of services offered in Nebraska, specifically Region V.
- \* A description of one program which was specifically designed to provide services to persons with severe or profound mental retardation, behavior or medical needs will be provided.
- \* What we have learned that works and does not work will be discussed.
- \* The Costs for this program will be summarized.
- \* Conclusions and recommendations will be shared.

BEFORE WE BEGIN

There are a variety of reasons why a system works or doesn't work for all of the people for whom it has been conceived. Given the limited scope of this paper, it is impossible for all of the components that are critical to a successful program designed to serve all persons regardless of the severity of their handicapping condition to be discussed. However, as those critical positive components or attitudes present themselves in this paper, they will be underlined for emphasis.

If I were to identify the primary reason why every region within Nebraska provides services to persons with severe/profound mental, behavioral and medical needs, it would be the attitude or philosophy, if you will, of the decision makers. Lou Brown has, perhaps, stated this philosophy best:

All individuals, regardless of the severity of their handicapping condition, will ultimately live in complex, heterogeneous integrated community settings.

Put simply, if decision makers believe that everyone will be served and integrated in the community, half of the struggle is over. In systems where that attitude is not embraced, I have seen every conceivable artificial barrier thrown up as a block to providing appropriate, integrated services for everyone.

With a philosophy that drives providers to develop services for all persons regardless of the severity of their handicapping condition must come service models which dictate that the more handicapped the individual the smaller the living environment must be. We have found this to be true not only of persons with severe or profound mental retardation but also those individuals who, in addition to their mental retardation, have severe medical or behavioral needs. This is not a minor observation. It is, I believe, one of the most critical factors which will influence the successful integration of persons with severe needs.

In harmony with a sound philosophy and a small living environment must come the consistent effort to tenaciously restrict and/or eliminate the future development of segregated workshop settings. The workshops of today are rapidly becoming a dead end placement for most persons with mental retardation regardless of their functioning level. It is critical to integrate persons so that they can learn real work skills in a real work environment.

Lest there be any doubt, Nebraska certainly does not have all of the answers as to what makes a good, comprehensive, totally integrated system. Like

Wolfensberger, I believe that for every good idea we've come up with, someone else has thought of ten better. This paper is presented as one commentary on things that have worked, and not worked, in Region V, with the hopes that there will be better ideas given back to us, so that we can improve the services offered in Nebraska.

#### BACKGROUND

There are six mental retardation regions (see cover map) in Nebraska which are controlled by local units of county government. There is one elected county official from each of the counties who sits as a member of the governing board for that particular region. The State Office of Mental Retardation serves as a conduit for funding, and sets and monitors the compliance with rules and regulations for the services delivered by the six regions.

The largest geographic regions have twenty-two counties. The smallest has five. The regional system is accountable to local government, many regulatory bodies and (because of the procedures which have been adopted) most of all to the individuals who are served.

A heavy emphasis has been placed on the involvement of consumers and consumer representatives, as well as professionals from related fields in an advisory capacity.

All of the regions have an area or local system of management which divides the region into smaller units. Control is, therefore, as close to the individual being served as is possible.



Lincoln. Without exception, every program serves persons with severe/profound mental retardation, behavioral and medical needs.

#### THE FAIRBURY PROGRAM

##### Why Was It Established

As a result of revenue made available by the State of Nebraska to place persons out of the institution and into community based mental retardation regions, Region V submitted a proposal to create a new area program which would serve persons with severe/profound mental retardation. In 1980, when this proposal was submitted, with few exceptions, the individuals remaining at the institution from Region V counties were persons who fell within this range of retardation.

While six other programs existed within the region at that time, all of which served many persons with this same level of retardation, concern over saturating any one community, the desire to expand the capacity of the agency, and the wish to serve other geographic parts of the region dictated the decision to establish a new program site.

##### How Was Fairbury Chosen

During the three years preceding the establishment of the Fairbury program, Region V had established three new rural programs. That experience, coupled with the specific needs of the persons moving into the program, led us to the conclusion (which continues for new program sites today) that any city chosen as a potential site must possess the following characteristics:

- \* There must be a community or junior college in or near the city for two reasons:
  - 1) we need a manpower pool from which to recruit and hire staff, and
  - 2) we want the individuals who come to this, or any of our programs, to

learn related skills, such as those taught through adult basic education, in the same environment as do other adults their age. We do not want to perpetuate segregation in the community by exclusively providing non-work related skill training in our centers. Consequently, some of the persons served in our programs attend classes through the community college, rather than receiving all of their training through Region V.

- \* There must be a reasonably comprehensive core of medical staff available in the community, either through a physicians' clinic or hospital. Many of the individuals being considered for the Fairbury program had complicating emotional and medical needs. The idea of transporting individuals who needed routine medical or psychological care an hour to an hour and a half to Lincoln was unacceptable.
- \* Available real estate for housing, as well as a training site must lend itself to adequately meeting the needs of the proposed core of services and must have the ability to absorb reasonable growth.
- \* The Chamber of Commerce, Mayor and other community leaders must be willing to assist us in securing sites for both the work site and the houses we would need.
- \* The city needs to be in a county that was centrally located near persons with mental retardation already identified in various communities who need services now or who will in the near future. While the initial group of persons served were from the institution, we had lists of individuals residing in communities who had applied for services, or who were in the school systems and would need services within the next two to five years. Obviously, consideration had to be given to meeting the needs of those individuals as well.

With those stipulations in mind, two cities were identified as meeting all of the criteria established by the Region.

It is not unusual for towns to "court" prospective businesses or industries, as they are the economic life of a community. A new industry brings new jobs and some new employees. They, in turn, buy or rent houses, purchase clothing and food, pay taxes, support churches and more. It occurred to us that our approach to the establishment of new area programs had, in the past, not been in line with our philosophy or our view of the type of business we really are. Consequently, we changed our approach. Instead of asking or expending large amounts of energy and time in order that we might "convince" communities of what a good "service" we provide (charity model) to a "special" population (pity model), we would:

- 1) Pick communities that met our established characteristics (listed above);
- 2) Approach them like any large (our smallest area program has a budget of \$400,000) industry and see what they could offer us; and
- 3) Let them convince our Board that they had the best all-around community for our new work site.

With that "bidding" approach in mind, Regional staff and local ARC representatives approached the Mayor and Chamber of Commerce for each of the cities. We provided information regarding the size of our budget, the number of persons we would employ, the number of facilities we would need, the type of industrial products that we produce and a description of the employees with mental retardation we would train.

In addition, we indicated what level of support we would expect from the city with respect to the identification of potential work and housing site locations, information on any zoning restrictions which might be a problem, and asked that they open doors for us with the medical, industrial and religious community, so

that initial conversations could begin. One of the cities had a population of 8,000 the other 4,800.

After all of the information was gathered, representatives from each city came to a meeting of the Region V Governing Board to "bid" on the receipt of the new program. In addition to slide shows and packets of information about each city, the two Mayors presented over 30 letters each, which offered support for the program and requested that their city be chosen as the new work site. Those letters were signed by every doctor, dentist and therapist in their respective cities. In addition, letters were submitted from lawyers, ministers, parents of handicapped persons, judges, colleges, ARCs, Rotary, Jaycees, Kiwanis, Optimists and Lions Clubs, the Department of Labor, fire departments and rescue squads, local welfare offices, public schools, newspapers, Industrial Development Corporations,, banks, and so on.

With that information in hand, the Governing Board chose the city of Fairbury, population 4,800. The presentations given by each city were comparable in almost every respect, however, the Fairbury area had more individuals waiting to come into services from both the institution and the community. Current and potential individual need proved to be the deciding factor in favor of the Fairbury location.

One of the exciting things we learned when we established this program was the if prospective community locations are given sufficient information, they will not only welcome a program: they will compete for it. The preliminary work in Fairbury helped the community understand its actual role in our program and set the stage for integrated activities later on.

#### Characteristics of the Employees

We had learned a good lesson about how to have new communities accept not only the program, but the employees as well. The community expected new workers

and a new industry. While they knew these workers would be severely and profoundly retarded, the image they were given was that of the mentally retarded person as a contributing member of the business community, not as a drain on the social or economic community.

Initially, twelve persons were chosen from the Region V population at the institution to be moved into the new program. In addition to these twelve individuals, three individuals from the community surrounding Fairbury were also served the first year.

Currently, the program serves 25 individuals, 11 males and 14 females. The average age of the individuals served is 36. The average time spent in an institution is 27 years. An abbreviated profile of the current individual characteristics follows:

<u>WORKER CHARACTERISTICS</u>	<u>TOTAL NUMBERS</u>
Level of Mental Retardation	
Mild	2
Moderate	2
Severe	7
Profound	14
Epilepsy	12
On Behavior Modifying Medications	8
Behavioral Outbursts	
0-1 Incident per Month	4
1-2 Incidents per Month	11
Once or More per Week	7
Once or More Daily	3
Self Help	
Independent	10
Verbal Prompts	8
Physical Assistance	5
Does Not Do	2

The preceding information reflects characteristics of individuals after being in the program for one year or more. There have been drastic changes in the abilities of these persons, particularly in the self help and behavioral areas.

The real story rests in the changes seen every day in both the individuals served and the agency itself. Again, the limits of this paper do not allow for detail here, sufficient it to say that the changes have been observable and significant.

#### Staff Characteristics

After determining who was going to be served and where they were going to receiving the service, we had to decide who the staff would be, and what models we would put into place.

When hiring staff, we looked for characteristics that are valuable in staff working with any group of persons with mental retardation, specifically:

Experience: The staff hired (vocational and residential) had an average of over three years experience in the field of mental retardation. In addition, we felt that staff must demonstrate skills in the areas of behavior management, environmental control such as multiple scheduling, stimulus control, data collection, multiple/individualized programming, and some staff needed to have skills in the area of manual communication.

Attitude and Philosophy: One of the most important characteristics we looked for was the attitude that the potential administrative staff had about the individuals whom they would be serving and about working with the public. We did not want someone who believed that it was enough to get people out of the institution, we wanted individuals who would not be satisfied until all of the individuals in the program were socially and vocationally integrated into the community. Individuals who had

good public relations skills and enjoyed that aspect of the job were desirable.

- \* Creativity: A third characteristic we looked for was a willingness to develop new approaches. We wanted staff to constantly search for ways in which the people served could tap into community resources, and thereby grow and develop beyond the limiting expectations imposed by past history. From the start, we really expected breakthroughs from the Fairbury program.

#### Service Models

In setting up a framework for delivery of services, the initial inclination was to continue doing what we had been doing elsewhere; namely, work sites and small living environments. To a great extent that is exactly what happened.

Of the 25 individuals placed in this program, six are involved in some off-site work environments. A description of the service models used follows.

#### Work Site

The work site is located in the semi-industrial section of the City. Contract work from local companies, as well as products which have been designed and marketed by Region V, are used to teach job related skills. Many of the contracts serve as a natural form of advertisement that the persons involved in this industry are working on real jobs and have a real income. However, competitive job placement is the goal for every individual in the program.

Dramatic improvement in skill acquisition has been seen since the contract work began. The work site model is certainly not ideal; however, through the work site model, additional, sometimes more subtle, benefits have occurred for the employees and the agency. A few examples of what individuals are involved in and how that has benefited the employees and the community follow:

During the 1981/82 fiscal year, 100 pallets were produced by the employees at the shop, and in 1982/83, 4,200 were produced and sold. Naturally, more people have learned the skills necessary to produce a product and more individuals are making money, some for the first time in their lives.

The shop also recycles aluminum cans. Last year over 2,300,000 cans were recycled, over \$20,609 was paid out to persons in the community and over 1,000 persons came into the center. These community customers have had the opportunity to see the real work that the employees are involved in, and interacted with the employees on a "reverse status" basis. That is, the normal community citizen is coming to the center to be given money, vs. the idea that people with mental retardation are only recipients of money from tax payers.

The most complicated product that this shop produces is braided horse and cattle halters. Over 200 of those units have been produced and sold.

One of the goals of this program is to gradually phase each individual out of the work site and into a competitive placement or a work station in industry. This goal is shared by all of the work sites in the Region. Where can an individual best learn work skills and habits than in a real job? That is the process by which we have all learned our professional skills. We must work toward making the industries and small businesses that already exist in the community our work sites.

In line with the belief that individuals should not be isolated in work activities centers, some of the training activities take place away from the work site. For example, the program has community contracts for lawn care, carpet cleaning and a news circular route. One individual is

placed at Headstart.

#### Homes

If your child were having difficulty learning in a school classroom of thirty individuals, would you want him/her moved into a class room of sixty? Obviously not. The same holds true for persons with mental retardation of any level or any behavioral or medical need. We have learned that group homes of eight to ten persons are too large. Two or three individuals living together with a staff person makes for a much richer learning environment. It's easier to teach, to control the environment, to integrate with your neighbors, to travel in a car (not a van), to go downtown, and to learn in that environment. The attention individuals require is more readily available if it has to be shared with only one or two other individuals.

Persons with severe behavioral needs, in addition to the severe or profound mental retardation, may need to start with a one-to-one living environment. As individuals adjust to controlling themselves and their environments, one or two roommates may be gradually added, if economically necessary and socially appropriate. As stated earlier, eighteen (18) individuals in the Fairbury work site came from an institution and now live in the small group living homes described below. The total number of individuals living in small group homes is twenty-one (21). Three (3) individuals live with their natural families and one individual lives in an Adult Family Home.

- \* Small Group Homes: Of the individuals living in group environments, fifteen (15) live in a home with two other roommates. All of the houses are staffed for 1 Full-time Equivalent (FTE) staff weekdays and 1 FTE staff weekends. In addition, part of the stipulations made by the institution, in order for individuals to move into the community, was that Region V would provide overnight awake supervision. That

stipulation was made for any individual who had had a seizure during the past five years, individuals who had to be "specialied" (taken to the toilet or had to be checked frequently), also for some people who were non verbal, or anyone who got up during the middle of the night. In every case, overnight awake staff were phased out of the small group homes after a 30 day period. The phase out was not done arbitrarily, rather, data was recorded and training initiated to eliminate the behaviors identified as necessitating the overnight awake staff.

Large Group Home: Six of the individuals live in a large group home (six person) which provides 2 FTE staff weekdays and 2 FTE staff weekends. In addition, overnight awake supervision is also being provided and has been for three years. However, it is projected that this staffing pattern will no longer be needed after January, 1984.

Adult Family Home: One individual lives in an Adult Family Home, which is similar to foster care for children. This alternative is provided with a family in a private home, licensed by the Department of Social Services (Welfare). Region V recruits, trains and monitors the provider.

#### Quality of Life

No matter what the size or cost of the (service) "model of choice" the most important concern should be the quality of life experienced by each person with mental retardation. When we evaluate our agencies or train our staff, one of the exercises we all participate in is listing those things which make our lives meaningful or good (money, friends, family, lovers, independence, control). We talk in terms of what normal individuals "X" age (as we grow older the sample age goes up) do to have fun, what it means to be a good neighbor, have money and shop where we please. From those lists we talk about how many of these experiences

persons with mental retardation participate in on a regular basis. What we are really trying to get to are those components that give our lives quality.

Some of the things we have done to improve the quality of life for individuals in the Fairbury program and other of our programs follow:

Individuals are involved with the community college in their Adult Basic Education Classes which is seen as a real status builder. The fact that some individuals are interested in going over to the "College" demonstrates the increase in self esteem and confidence many of the employees have gained during a short three year period of time.

One of the Region's goals is to spin most or all of the training over to technical, junior or community colleges as work sites phase down and out.

Some of the employees, when first moving to Fairbury, had never gone shopping or attended a church service. In many cases, behavioral outbursts precluded training during normal "open" hours for merchants or church services. The business and ministerial alliance responded openly and positively. We did the task analysis and program design, they opened their businesses during off hours and held special church services until everyone was integrated into the normal business and church environments. That process took three years, but it is now complete, and no "special" or segregated training takes place in these areas. The only exception will be new individuals who enter the program and who may need this unusually intensive training.

Leisure activities have also provided many firsts in peoples' lives.

For many of the employees the last three years have given them the first opportunity to take regular vacations, catch fish, go to dances or concerts, participate in softball games, see rodeos, the list goes on

and on. The obvious issues with leisure time activities center around frequency, variety, integrated activities and SMALL numbers of persons with mental retardation traveling together.

As a result of the internal evaluation done on each agency in Region V, a heavy emphasis has been placed on persons with mental retardation being given the opportunity to initiate and/or participate in community service activities. Instead of always expecting the community to give to us, we are expecting our staff and employees to give back to the community. Examples of activities are as varied as what each community does for its own. For example, some communities have held CROP Walks (to raise money for an international relief program and two local gardening projects. In response to the request from the Ministerial Association, the Employee (Client) Advisory Board at Fairbury decided to participate in the fund raising event) and some local employees have participated in them. Others have chosen to adopt a Senator (political action) or adopt a neighbor (elderly contact and call program). Others prefer not to be so formal and do a lot of contact with persons of their choice on their own.

#### Costs

Fairbury is the second (out of seven programs) most expensive program operated by Region V. That is due, primarily, to the small size of the program and to the needs of the individuals being served there. In order for that to be meaningful at all, some detail is provided as follows:

## FAIRBURY AVERAGE PER PERSON COSTS

<u>Service</u>	<u>Costs</u>
Vocational	\$ 6,953
Residential	14,879
Transportation	491
Administration	2,636
Social Services	568
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Total	\$26,039

### Conclusions/Recommendations

After describing one experience with the establishment of a program which serves primarily persons with severe/profound mental retardation, I would like to share a few additional recommendations for those of you considering the establishment of similar services. I will try not to duplicate recommendations given in the body of the paper.

I. Serve a Cross Section of Developmental Needs: Develop Staff Expertise and Build Budgets Slowly.

This is probably one of the most important decisions that can be made with respect to the ultimate capacity of a system. If you take a cross section of individuals with varying characteristics which would include developmental levels, medical and behavioral needs, technology spreads and budgets grow in a steady, competent fashion. For example, if two individuals with severe behavioral disorders are placed in an agency one year, a core of staff (let's say four) can be trained to work with and support those individuals as they learn and adjust to community living. At the same time, staff will develop further confidence and skills as they design programs and adapt environments

intended to enhance the success of the persons with whom they work. The following year, you could take an additional four individuals with behavioral needs as the original core of four staff persons train eight additional staff to work with those new persons. As time passes, individuals who were once seen as extremely difficult to serve become a routine challenge to staff who are confident of their ability to adapt behaviors. Technology spreads as individuals who were once seen as "residual institutional populations" become integrated into the community.

Another advantage of taking individuals with varying needs is that budgets will grow steadily over time rather than peaking when more "difficult" populations are finally served. There is no doubt that some individuals will need more intensive staffing patterns and therefore cost more than other, less involved persons. If, over years, you build those staffing costs into your budget, people with mental retardation will not have to bear the burden of "being too expensive to serve". Averaging costs over numbers of individuals with varying needs, generally, makes for a cost that can be justified to boards and legislators. Whereas, averaging costs over a group of individuals who have only high needs seems to stimulate calls for conservative fiscal restraint and larger institutions for "those" people. It is our responsibility, as administrators, to act responsibly so that groups of individuals don't get set up to fail on fiscal issues they can not possibly control.

## II. Integrated Environments and Role Models are Critical.

I would state clearly that clustering persons with like needs, as we did in Fairbury, is NOT the way it should be done. A cross section of developmental needs should not only be taken but should be placed together. Segregation of any kind, should be avoided. That goes for segregating persons with high

needs from persons with low needs. Role models are lost, inappropriate behaviors are shared and modeled.

III. Use the Changing Technology with the explosion in computer technology and the advances in bio-engineering, great strides are being made in the area of services to persons with severe/profound mental and physical disorders. There are many "tools" that can be used today to make learning and improvement much easier for both the worker and the staff. We would be remiss if we did not take advantage of technological advances.

IV. Consistent, Structured Programming is a must. Programs will have to be designed and run based on seconds not minutes. The task analysis will have to be broken down into much smaller steps. Thought will have to be given to the jigs used to compensate for severe physical impairments. The rest of the principles appear to be the same.

V. Use Community Resources:

Rather than restate what has already been gone over in the paper, I would summarize by stating that the vision you have of what you are will, to a large extent, be embraced by the community. If you view yourself as an industry, then use community organizations, mayors and city council's as industry would and let them do the ground work for you if your are just coming into that community.

If you are already established, use community organizations as a means of doing some public education, employee training, and a group from which support can be mustered.

Community colleges, technical colleges, and universities are a tremendous resource for us and may, someday, become the training sites as our workshops close down.

Medical Services in many instances here in Nebraska have improved in the

rural communities where we have established programs. Where some communities did not have access to anaesthesiologist, we have joined with the local medical community to bring in such a service/person. The entire area benefits. Use the Media like anyone interested in enhancing the image of his business would. As you elevate the status of your business, you also elevate the status of your staff and employees. Give the media legitimate stories, geared to meet your image (industry) or to tell your story (training workers) or to get your employees jobs outside of your work sites. As you develop or continue programs for persons with severe/profound mental retardation and come to your own conclusions please share them with us!

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