Cluster Homes:
A Community for
Profoundly and Severely
Retarded Persons

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This article discusses community residences that in 1983 replaced two large institutional facilities for retarded persons in Florida. Twenty-six of these residences, or clusters, usually housing 24 clients each, are located throughout the state. The clusters are designed to normalize the living conditions of the mentally retarded, increase their safety, and place them close to society and their families. Medical and social services, including occupational therapy, are made available to all residents of the clusters. This article focuses on one of these clusters, with special emphasis on the role and scope of occupational therapy services within this unique setting. Special problems and experiences encountered in the delivery of occupational therapy services to the profoundly and severely retarded clients in the clusters are explored.

Nationally, a clear trend has continued in recent years with the movement of institutionalized, mentally retarded individuals from very large, remote centers to smaller, community-centered facilities (Lakin, Krantz, Bruininks, Clumpner, & Hill, 1982). Bjaanes and Butler (1974) noted, "Central to this trend is the assumption that community care facilities provide a relatively more 'normal' environment, and that this type of environment is more conducive to personal development and 'normalization' than are total institutions" (p. 429).

Although smaller facilities have great potential for providing improved living conditions and more personalized care, occupational therapists in these facilities face unique issues regarding the role, scope, and implementation of occupational therapy programs. The following case study highlights the development of one type of community residence. It describes the model of occupational therapy practice currently used to provide services for the facility's profoundly and severely retarded residents.

Review of the Literature

The number of mentally retarded persons residing in public residential facilities increased from a low of less than 10,000 in 1880 to a high of 194,650 in 1967. Since 1967, deinstitutionalization and movement of clients to community residential facilities have caused a steady decline in population (Conroy, 1977; Lakin et al., 1982). In 1982, 52.8% of the mentally retarded (128,637) lived in public residential facilities, and 47.2% lived in private facilities. Only 22.3% lived in group residences with 6 to 63 clients, whereas the vast majority (58.4%) resided in facilities with more than 63 residents (Hauber et al., 1984).

Bruininks, Hauber, and Kudla's (1980) 1977 national survey of community residential facilities (CRFs) found that more than one half (2,410) of all CRFs were opened between January 1, 1973, and June 30, 1977, and that 1.6% of the facilities had 21 to 25 beds and 88.2% of the facilities had 1 to 20 beds. Severely retarded persons constituted 21.8% of the residents in CRFs, with only 10.6% of the residents classified as profoundly retarded. In contrast, other studies around the same time found that severely retarded persons constituted 30% of the public residential population, and the profoundly retarded, 44% (Nelson & Crocker, 1978; Scheerenberger, 1976). A 1978 national study of release patterns from public residential facilities showed that the severely and profoundly retarded constituted one half of the persons transferred to community facilities in that year, but that this group also constituted one half of the persons readmitted to large public institutions (Best-Sigford, Bruininks, Lakin, Hill, & Heal, 1982). The researchers also noted that...
the types of adaptations needed, if the deinstitutionalization process is to continue reducing the numbers of people confined to institutions, are clear. Primary among these is the need to locate, develop, and adequately fund extra-institutional alternatives for severely/profoundly retarded people. (p. 139)

The concept of normalization, advocated by Wolfensberger (1972), is based on the assumption that retarded persons should be afforded the opportunity to live lives as normal as possible. This concept has long been the rationale behind replacing large institutions with smaller living units or group homes (Alexander, Huganir, & Zigler, 1985).

Do smaller residences and supposedly "normal" environments truly facilitate better development of retarded persons? Eyman, Demaine, and Lei (1979) found that factors such as administrative policies, environmental blending of the facility with the neighborhood, location and proximity of services, and comfort and appearance seemed to contribute significantly to growth in adaptive behavior. A 1981 study of changes in residents who were moved from large to smaller institutions found improvement in management practices and staff-resident interaction with accompanying improvement in adaptive behavior of residents who had come from more restricted settings (Heming, Lavender, & Pill, 1981). A 1970 study of three types of "homelike domestic environments" built to house small groups of retarded residents in England found less institutionlike management practices than in larger facilities (Dalgleish, 1983).

Alexander et al. (1985), comparing size of institutions with impact on cognitive and personality variables, concluded that although residents of large institutions showed increasing wariness of strangers over time, residents of large and small institutions did not differ in dependency or measures of success in a learning task. Alexander et al. further concluded that researchers should look closely at social interactions within the institutions rather than just at the type of setting. Raynes (1980) cautioned that the exclusive grouping of severely and profoundly retarded residents in a living unit might have negative effects on staff morale and consequently on the stimulation and development of residents. Menolascino and McGee (1981) noted that

true deinstitutionalization is not the mere reduction in the number of persons residing in institutions, but it is the individualized placement of each mentally retarded person into a community-based delivery system which ensures the physical, spiritual, and developmental well being of the mentally retarded person during the individual's lifespan. (p. 218)

Case History

Until 1983, Florida housed mentally retarded citizens in large institutions, as did most other states. In the 1960s, vacant tuberculosis hospitals in Tallahassee and Orlando were converted for use as residences for a portion of the state's mentally retarded population. These complexes housed approximately 300 and 650 clients, respectively. However, in 1979, a class-action suit filed on behalf of the clients at the Orlando institution cited a lack of proper seating, lack of physical therapy programming for clients, and lack of feeding programs (as evidenced by an inordinate number of clients receiving nutrition through nasogastric and gastrostomy tubes). Also at issue were safety concerns arising from the multistory design of the buildings.

As part of an out-of-court settlement reached in 1983, the state closed both the facility at Tallahassee and the contested Orlando facility. The plan was to place clients in newly built housing designed to optimize normalization by providing a more homelike setting. Consultants for the Florida Health and Rehabilitation Services helped to arrive at the cluster model, each cluster would contain three 3,000-square-foot, one-story houses, providing residence for a total of 24 clients. The houses would be of contemporary-rustic design to fit into the environment.

Twenty-six clusters were built. Constructed in both rural and urban settings throughout the state, the clusters were located near communities and family members whenever possible. Family involvement was encouraged and supported.

The Lake City Cluster

Although owned and financed by the state, nearly all the clusters are managed and staffed by private vendors on contract. The Lake City cluster staffing pattern is typical of many Florida clusters. Hired as full-time staff are an administrator, a director of nurses, direct care staff, cooks, a program director, a behavior specialist, house managers, a social worker, a recreational therapy aide, a maintenance person, a secretary, and housekeepers. Hired as consultants, under contract and on a part-time basis, are a physician, dentist, pharmacist, psychologist, audiologist, dietitian, physical therapist, speech therapist, and occupational therapist.

The Lake City cluster is built on approximately 10 acres, in a middle-class, rural community. There is no sign in front of the property to identify the nature of the residence. One wing of each L-shaped house in the cluster has four bedrooms and two baths. Each bedroom is occupied by two residents and is decorated according to the desires of the clients or their families. Personal items are welcomed.

The other wing in each house is used for daily activities and administrative needs. It has a laundry room, storage rooms, an office, a combined nurses' room and drug room, a sitting room for watching television and visiting with relatives, a bathroom for employees, a large activity room that also serves as...
the dining area, and a sun room. The kitchen adjoins the activity room. Every effort has been made to normalize the surroundings, to the extent that there are no dedicated therapy or treatment areas. One closet in the cluster is used for occupational therapy supplies, and the occupational therapist shares an 8-by-10-foot office with all the other consultants, which is used for administrative purposes.

The Clients
The residents of Florida's various clusters are not homogeneous. In addition to the severely and profoundly mentally retarded who are nonambulatory, there are ambulatory clients, who may or may not have job training possibilities. Some clients are children, some are blind, and some have serious medical problems. The clients at Lake City are profoundly and severely retarded. This article focuses on the delivery of services to this group.

The profoundly retarded Lake City clients, without exception, have physical disabilities associated with their mental retardation. Although a few clients are able to perform wheelchair transfers and to walk for short distances, most are entirely wheelchair dependent. Wheelchairs used vary from standard folding wheelchairs to those customized to fit the client's particular size and needs.

Approximately one third of the residents have limited range of motion in the upper extremities, including contractures at the wrist or fingers and occasionally in the elbow. Extreme flexion deformities of the wrist, leading to hand hygiene problems, are common. Feeding difficulties associated with delayed or abnormal oral-motor development are also often found. Sensory deficits leading to pseudocortical blindness, blindness due to syphilis or early head trauma, and seizures also must be treated.

Other problems seen are marked tantrums and repetitive self-injurious behaviors, psychiatric and psychological abnormalities, autistic-like behaviors, self-stimulatory behaviors that interfere with other functions, abnormal sleep patterns, and refusal to eat.

Occupational Therapy Programming
Federal and state guidelines require that occupational therapy be available to all clients who need it, and therapy must be carried out under the direct supervision of a registered occupational therapist. In Florida, the occupational therapist must be licensed. An annual habilitation plan developed by the interdisciplinary team, which includes the occupational therapist, indicates the occupational therapy needs.

All professionals must use a standard evaluation instrument. In the Lake City cluster, state-approved forms for assessing occupational therapy and feeding needs are used. Basically, the occupational therapy assessment covers range of motion, splinting, reflex abnormalities, muscle tone and pattern, sensory abilities, developmental motor skills, and fine motor coordination of the upper extremity. The feeding assessment covers positioning, feeding skills, and feeding process.

Once the assets and deficits of the client have been determined, goals in occupational therapy are recommended for team approval. Goals must be measurable and achievable within a period of 1 year. It is the responsibility of the occupational therapist to write programs that will enable the client to attain approved goals. For each goal established, the therapist writes a short-term objective (STO) and accompanying treatment plan. Each STO is written in simple, step-by-step language and has a criterion (e.g., the client will move his tongue left and right on five of five trials for 10 consecutive sessions). Data relevant to the STO are recorded after each treatment session.

Because the Lake City clients are profoundly and severely retarded and have related physical problems, most goals address deficits rather than assets. As the clients develop, of course, assets should receive more emphasis.

Special Problems
The cluster's administrative procedures and applicable state and federal regulations require more paperwork than is customary in many occupational therapy situations, so the occupational therapist's time during a consultation visit cannot be fully devoted to direct treatment procedures. Consequently, after each STO and corresponding treatment plan is written, the occupational therapist instructs the care giver on the proper implementation of the program. This approach, which is consistent with the principles of normalization, is tantamount to training a family member in the care of the disabled person and has proved very successful. The occupational therapist monitors the program directly at least once a month and writes a monthly progress note based on observation of the client and review of data recorded as part of the treatment program. In addition, the occupational therapist attends, as appropriate, monthly and quarterly review meetings for each client.

Most clients initially seen in the cluster were transferred from the two closed mental retardation facilities and had extremely limited prior exposure to therapy services. During the first 2 years of the occupational therapy program at the cluster, most goals were directed toward oral facilitation for the development of eating skills, splinting, wheelchair positioning, sensory stimulation, and muscle reeducation.

On admission to the cluster, most clients lacked the basic oral facilitation skills of tongue control and
chewing. Through occupational therapy, most developed proper tongue control. Several clients learned to chew and progressed from blended to diced diets. A comparison of body weight at the time of entrance into the cluster and 1 year later showed a 9% increase in the mean weight, which brought clients within the range of their ideal body weights. A paired t test (n = 24, df = 23) showed this change to be significant (p < .01).

Improvements in clients' skills are not the only possible explanation for the apparent success of the occupational therapy, however. For example, direct-care staff received training in proper methods of feeding clients. Also, the dietitian and dietary staff were kept informed about client's oral functions and corresponding diet consistency needs. Finally, an effort to determine and accommodate individual clients' likes and dislikes of certain foods must also be acknowledged.

Proper upright positioning is the exception, rather than the rule, with multiply handicapped, profoundly retarded clients. For feeding and participation in other routine daily activities, a good upright position in the wheelchair is essential. Yet clients in large institutions, with low care giver-to-client ratios, are not likely to receive much individual help with their seating position. After transfer into the cluster, these clients are almost always in the reclined position. In the clusters, it is necessary to work closely with physical therapists and with outside wheelchair vendors to adapt wheelchairs to accommodate physical deformities, because space and cost-effectiveness issues make in-house facilities for wheelchair work and construction impractical. At this time, the state is attempting to develop regional seating teams to help meet the need for specialized, adaptive seating. Meanwhile, in-service training, STO programming, and daily reminders are teaching care givers to seat clients in an appropriate upright position.

One third of the clients in the cluster have hand deformities that require splinting. Excessive wrist flexion and finger contractures cause hygiene problems, which are very prevalent. A resting splint fitted to achieve as near a normal position as possible helps to eliminate this problem. Splints are worn during the day, 1 or 2 hours on, and 1 hour off. This schedule is counter to the usual practice of applying positioning splints at night, but splints can be monitored better in the daytime when staff coverage is better, and low-functioning clients are particularly likely to lie on a splinted hand at night, causing skin breakdown. Because of low-level cognition, many clients act defensively after they have been fitted for a splint. They do, however, adjust after a period of time. Fitting this population is somewhat different from fitting the typical client in occupational therapy because the severe deformities that are found distort anatomical relationships. However, with a little ingenuity all clients can be fitted.

Mentally retarded persons who are unable to see, but whose blindness has no organic basis, have what is called cortical blindness, or pseudocortical blindness. At least three clients have had this condition improve after 1 or more years in this cluster. These clients, formerly classified as legally blind, are now able to make direct eye contact with persons and objects; they are able to track, respond to facial expressions of the care giver, and watch and respond to television. Although it is not clear exactly what has brought about this change, several factors may have facilitated improvement. Upright positioning places the clients in a better position to perceive the environment, with better sensory input. Also, the increased individual and group activity in the cluster enriches the clients' lives and appears to make their surroundings more meaningful to them. Care givers give the clients considerable attention both in informal interaction and in regularly scheduled activity and treatment programs. This attention appears to help the clients trust their environment and be less defensive than they were in the larger institutions. In general, the normalization of the surroundings apparently helps to eliminate the barrier that causes clients to withdraw into themselves.

The cluster presents certain limitations in the delivery of occupational therapy services. In their drive to create a normal, homelike environment, the planners apparently forgot the programmatic and treatment needs of the clients, especially the needs of low-functioning and wheelchair-bound clients. Space for treatment and positioning of clients out of the wheelchairs is extremely limited, particularly because day areas of the houses have multiple uses (e.g., one room is used for meals, recreation, and treatment). Office space is also limited, considering the unusually high documentation requirements for federal reimbursement. Finally, the small, localized settings lose the economies of scale enjoyed by the large institutions. Small size has a profound effect on the purchase of equipment, supplies, and professional expertise.

Conclusions

So far, the community-based cluster concept has appeared to work well for severely and profoundly mentally retarded clients in Lake City. Treatment in the clusters is of better quality and more individualized than in the larger state institutions. In Lake City, this improvement has been reflected in significant changes in clients' nutritional status and responsiveness to sensory input.

The role of occupational therapy in the clusters
is essentially a new one, however. Much of the service
is delivered indirectly, on a consultative basis, which
requires intensive in-service training of care givers,
with step-by-step treatment programs that are de­
signed and written simply and concisely. Moreover,
free flow of communication between the therapist
and care givers is extremely important, so that treat­
ment programs can be frequently adjusted to the
client's changing needs.

The therapist in this setting must become partic­
ularly adept in managing time and must develop
organizational skills in order to keep current with
requirements for documentation of programs and
progress for federal reimbursement. The authors have
found that carefully organizing this phase of practice
free time for the more personally rewarding direct
involvement with clients.

The normalized environment requires occupa­tional therapy services to be delivered without the
benefit of a specified treatment area or office facili­
ties. In this regard, the setup is not unlike the delivery
of services through home health agencies. Economies
of scale are lost to the small facilities, and the therapist
is forced to look to outside vendors for ready-made
adaptive equipment and wheelchairs. Finding ven­
dors can be a significant problem for therapists at
facilities located away from urban centers.

At the clusters, the complex problems presented
by the severely and profoundly retarded clients cou­
pled with the demands for advanced organizational
abilities and team-related experience suggest the
need for experienced therapists. Small facilities, how­
ever, seldom have the financial resources necessary
to support full-time staff at this level. Hiring therapists
as part-time consultants has been a successful solution
to this problem.

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