

Adaptive Housing: A Boon for the Handicapped

SANDRA F. LEZBERG

PROVIDERS of health care usually believe that they have the skills and knowledge necessary to provide some form of relief to patients they are treating. Their remedies, however, are usually offered in their offices or treatment centers far removed from the environments in which their patients or clients spend most of their time. A clinician does not routinely inquire how a patient with a particular set of functional problems manages at home. When the patient happens to be a child with a chronic handicap, it is taken for granted that the parents manage *for* the child, or that there are no particular problems posed by the home environment. Usually, health care providers do not start considering what support services a family might require to remain intact and to continue coping with the child at home until the family is breaking apart or talking about placing the child in an institution.

Recently, caregivers with a focus on preventive approaches have begun to pursue strategies that minimize the handicapping effects of a chronic condition and maximize the abilities of patients to function independently. Housing is an important determinant of how able or disabled a person with a physical handicap actually is. Someone who must spend an inordinate amount of energy merely to move around the house is unlikely to make the effort to get out of the house. When the individual is a child, a threshold or just a step or two may represent barriers to learning experiences and prevent the attainment of skills usually achieved through exploration and manipulation of the environment. Thus the environment rather than the mobility impairment may limit a child's developmental level and foster passivity and helplessness.

The Division of Family Health Services (FHS) of the Massachusetts Department of Public Health recognizes the significant changes that an enabling environment may make in a family's daily management of a child with a mobility impairment. Not only is the child's independence

encouraged, but the family may also enjoy a less burdensome quality of life. Most families accept the wear and tear of lifting and carrying their children as a by-product of parenting. The child gradually gets heavier and parents adjust to the situation as part of their responsibility. In our experience with families raising children with handicaps, we find that parents push themselves to their limit until a crisis is provoked and potential in-home remedies are too late.

OBJECTIVES

In an effort to prevent some of these crises, FHS has undertaken a program of housing adaptations that began in 1984 as a direct result of funding from the Federal Emergency Jobs Bill. The objectives of this program are to enable children with handicaps to become more independent in their homes and to facilitate their getting into and out of their homes. Families with mobility-impaired children from birth to age 18 who are Massachusetts residents are eligible for technical assistance from the Adaptive Housing Program. The services have included the installation of walkways and ramps, modification of bathrooms, exterior and interior lifts, elimination of thresholds, widened doorways, and environmental control units. The goals of the program are to help create enabling environments for children with handicaps and to make it practical for them to use supportive programs in their communities. Through deliberate environmental design, opportunities are created for children to participate in a variety of experiences, to benefit from opportunities for socialization, and to enhance their skills and control their own lives. Their families can thereby be relieved of a great deal of lifting and carrying, see their children make gains in self-esteem, and acquire ongoing respite while their children are engaged in community programs. Furthermore, it is important that the family not be uprooted from the community because of the needs of the child who is handicapped. The ties and support that families have from friends, relatives and local agencies should not be disrupted if at all possible. Frequently, families forego opportunities to relocate to accessible housing either because it is designed for the elderly or it is located in a remote area at a distance from valued support systems and effective networks.

SELECTION OF FAMILIES

During the first two years of operation the Division's Adaptive Housing Program served 45 families in 33 communities representing all areas of

the Commonwealth. The Division's service delivery staff works locally from regional health offices. Families become known to regional staffs when their children receive either specialty medical care through the Services for Handicapped Children clinic program or social work case-management services in conjunction with their Supplemental Security Income (SSI) eligibility. Additional families are referred to the regional offices of FHS from social service agencies, public and private health care facilities, and special education settings. Each regional health office constitutes its own selection committee, usually with a physical or occupational therapist, social worker, and case manager who review all the cases and establish the priority of each applicant. The application provides members of the committee with information about the child's height and weight, abilities and dependencies, and the restrictions imposed by the environment.

Values are assigned to child-centered and family-centered variables so that the committee may develop an objective standard for selecting the homes to be visited. The highest score possible is fifty points from the maximum of twenty-five each for the child-centered variables and the family-centered variables. A maximum of five points each may be given to educational, recreational and social activities outside the home that the child cannot do at present, but would be capable of doing if changes were made in the home environment. A maximum of ten points may be given to the effects of proposed home modification on increasing the child's level of participation in self-care tasks. The family-centered variables include a maximum of five points each for the time spent by other family members assisting the child with activities of daily living, the impact of this dependence on the family's lifestyle, and the diversion of common family living space. A maximum of ten points may be given for the strains of lifting and carrying the child that would be alleviated by home modification. Applicants are given priority according to their totals. An applicant that is not selected in a given fiscal year but has almost as many points as a chosen family might be carried into the next year's cycle as first priority.

A professional who is involved in providing the child's care and knows the family visits the home with the project manager of the Adaptive Housing Program. With the family they discuss options for changes that would create a more enabling environment. Plans are developed and cost estimates are obtained. Modifications that add value to the property such as enlarging its dimensions cannot be considered. All families of mobility-

impaired children are eligible for evaluation of their homes. Suggestions for change will be provided regardless of family income, and financing guidance may be given to the family that undertakes a project independently. If a family is then determined to be financially eligible, the Adaptive Housing Program will go further and obtain the contractor, supervise the construction, provide financial assistance, and evaluate the effectiveness of the adaptations. Although most recipient families owned their homes, families who rented were served if they obtained permission from owners to make changes. Adaptations were made on currently occupied, existing housing, not on new housing units. All of the children were mobility-impaired and most were totally wheelchair-dependent. Their ages ranged from 4 to 17 years and their diagnoses included:

- 23 cerebral palsy, including 3 with seizure disorders and one with blindness;
- 4 congenital encephalopathy;
- 3 myelodysplasia;
- 3 muscular dystrophy;
- 2 spinal cord dysfunction secondary to tumor resection;
- 1 near-drowning;
- 1 osteogenesis imperfecta;
- 1 McCune–Albright syndrome;
- 1 juvenile rheumatoid arthritis
- 1 arthrogyrosis;
- 1 transverse myelitis;
- 1 Rubella syndrome;
- 1 C 5–6 trauma;
- 1 cerebral blood clot;
- 1 ventilator-dependent.

ADAPTATIONS AND THEIR RESULTS

The child who was ventilator-dependent had spent three of his four years of life in an acute-care hospital until a ramp and a stair lift and 24-hour nursing services were put in place. A young woman with cerebral palsy required the assistance of two people for bathing until shower doors were removed and a hand-held shower and sliding bath seat were installed. Brothers with muscular dystrophy used wheelchairs that were too wide to permit access to the bathroom. With a widened doorway, more ver-

satellite plumbing accessories, and improved access to the sink, they are now safely independent in all grooming skills. Costs ranged from a low of \$79 for a hand-held shower to a high of \$7,243 for an exterior lift, with an average cost of \$3,647 per family. Changes in the homes included:

- 17 ramps;
- 9 exterior hydraulic vertical lifts;
- 8 walkways;
- 4 windows converted to doors;
- 4 tub rails and seats;
- 2 interior stairglide vertical lifts;
- 1 bathroom converted to roll-in shower.

While these were the primary interventions, most families received several small additional adaptations such as the addition of grab bars, elimination of thresholds, and revision of faucet handles, doorknobs and door hinges, light switch extenders, intercom controls, and environmental control units that turn appliances on and off. When completing evaluation forms, 34 families reported easier, safer, or more independent access and egress for the child, 39 parents told us their back strain had been diminished by the reduced need for lifting and carrying, and 43 said the whole family was benefiting from the adaptations; all of the children were attending at least one additional community program. Parents no longer had to be summoned countless times to move a child from room to room, in or out of doors, or to turn on a light or radio. All of the children were functioning more independently, taking care of more of their own grooming and other personal needs, and enjoying privacy they had never experienced. They had greater self-esteem and were demonstrating greater expectations and capabilities. Members of our teams often witnessed children getting into or out of the house independently for the first time and saw faces beaming with pride. One parent completing the evaluation form answered the question about changes that resulted from the adaptation by saying glowingly, "I can't describe it." In some instances children can be independent with a degree of safety that gives their families new-found peace of mind. Frequently, tasks and activities that were beyond the realm of possibility became manageable. Children who required the assistance of two caregivers can now be tended by one without the necessity of carrying the child and the wheelchair separately.

THE NEED FOR ADAPTIVE HOUSING

No other environment provides the loving care that parents and surrogate families in home-like settings are capable of bringing to children. Moreover, children are most likely to thrive when they are benefiting from home and community settings. Yet their parents, their most effective resources and advocates, are vulnerable to burn-out from the stresses of intensive care-giving, particularly as their children get larger and heavier and they themselves get older. Our Division has been consistently committed to providing home and community-based services to support families who want their children at home rather than in institutions. Housing adaptations that remove architectural barriers represent a cost-effective intervention that involves one-time charges with immediate and multiple rewards. Such interventions tell families that we respect their choice and want to support their efforts. Traditionally, government steps in with services only after families give up, instead of rewarding or supplementing the efforts of families who manage their children at home year after year. One year's cost of care for a child institutionalized in Massachusetts is estimated to be \$36,000. Perversely, these public dollars flow routinely, whereas relatively small amounts of money for one-time charges are not available to the most effective, least costly caregivers of all.

In 1980, the New York City Department of Housing Preservation and Development awarded a contract to United Cerebral Palsy of New York City (UCP) for Project Open House, a pilot program to remove architectural barriers from the dwellings of disabled persons. Members of a parents' group at UCP had described the difficulties in caring for their developmentally disabled children at home. "The lack of accessible housing often left institutionalization as the only viable solution" (1). In Sweden, a modified cost benefit analysis revealed that there usually were "reductions in the consumption of nursing care, home attendant care, and accidents from housing adaptations for the elderly" (2). A study carried out for the Department of Housing and Urban Development that reviewed "cost estimates for eliminating architectural barriers through renovations and redesign in the cities of Buffalo, Syracuse and Utica, New York revealed benefits amounting to 13 to 22 times the level of costs formulated on the market value of personal assistance" (3).

While many efforts are under way to ensure accessibility to newly constructed public buildings by the physically handicapped, the blind, the deaf, and the elderly, there is far less attention being paid to home

environments. Furthermore, "The growing body of information on physical access focuses on adults using wheelchairs and offers little help to families coping with a mobility-impaired child, with a blind toddler, or with a child who may have one or more of a wide range of other disabilities" (4). Given only institutional models, families must become inventors, in the absence of precedent for home adaptation (5).

It is the hope of the Division of Family Health Services that we will continue to provide housing adaptations as a support service to families. We have done cost-sharing on mutual clients with other state agencies and intend to expand on this cooperative strategy. We are also developing educational aids that we hope will sensitize families and other caregivers about barriers to independence and a range of solutions to improve a child's mobility. Our brochure advises families of young children to select accessible housing and plan for the time when their children are larger. Ultimately, we hope that agencies and advocates will integrate housing into individualized case planning that will be responsive to the needs of families with young children, individuals capable of independent living, and the elderly.

Health care professionals must increasingly recognize the appropriateness of adaptive housing as a component of developmental intervention. Furthermore, there must be acceptance of the health department's role in providing such adaptation as an integral component of the continuum of supportive services.

REFERENCES

1. Colvin, M. E. and Korn, T. L. "Eliminating Barriers to the Disabled," *Am. J. Occupational Therapy* 38 (1984): 748-53.
2. Ratzka, A. D. "The Costs of Disabling Environments." Stockholm, Sweden, Swedish Council for Building Research, 1984.
3. Chollet, D. J. "Cost-Benefit Analysis of Accessibility." Washington, DC, Syracuse University, NY, for Department of Housing and Urban Development, 1979.
4. Ostroff, E. "Adaptive Home Design for Families." Boston, MA, Adaptive Environments Center, Inc., 1986.
5. Lewis, B. E. "Inventors, Explorers, Experimenters: How Parents Adapt Homes for Children with Mobility Problems." Cambridge, MA, Doctoral Thesis, Department of Urban Studies and Planning, Massachusetts Institute of Technology, 1985.

BIBLIOGRAPHY

- Agosta, J. M., Allard, M. A., Bradley, V. J., Rugg, A., Ashbaugh, J., Mace, R., and Long, M. *Assessing Housing Needs for Persons with Disabilities: A Guide and Resource Book*. Boston, MA: Human Services Research Institute, 1984.
- Burton, L. *The Family Life of Sick Children: A Study of Families Coping with Chronic Childhood Disease*. London: Routledge and Kegan Paul, 1975.
- De Jong, G. and Litchez, R. "Physical Disability and Public Policy," *Scientific American* 248 (1983): 40-49.
- De Jong, G. *Environmental Accessibility and Independent Living Outcomes*. E. Lansing, Michigan: Michigan State University, University Center for International Rehabilitation, 1981.
- Dunn, P. *The Homes Research Project: The Need for Housing Adaptations in Massachusetts*. Boston, MA: Adaptive Environments Center Inc., 1985.
- Hayes, G. *The Source Book for the Disabled*. New York and London: Paddington Press Ltd., 1979.
- Osberg, S., Corcoran, P. J., De Jong, G., and Ostroff, E. "Environmental Barriers and the Neurologically Impaired Patient," *Seminars in Neurology* (1983): 180-94.
- Perlman, R. *Family Home Care: Critical Issues for Services and Policies*. New York: Haworth Press, 1983.
- Zeitlin, P. "Small Changes Make A Big Difference: Adapting the Home Environment," *The Boston Parents' Paper* 11 (1986): 1.

ABSTRACT

The environments in which multiply-handicapped children live frequently limit their activities beyond the restrictions imposed by the disabilities. Children with mobility impairments, deterred from exploration of their environments, may have their learning further hampered by the design of their homes. In 1984 the Division of Family Health Services of the Massachusetts Department of Public Health initiated an Adaptive Housing Program. It is our belief that health care professionals must recognize the need for adaptive housing and accept its appropriateness as a support service.