Eliminating Barriers to the Disabled

(activities of daily living, facility design and construction, occupational therapy, self-help devices)

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Project Open House provides for the removal of architectural barriers in the homes of disabled low and moderate income New York City dwellers. This program was developed as a cooperative effort between United Cerebral Palsy of New York City, Inc., the New York City Mayor's Office for the Handicapped, and the Department of Housing Preservation and Development. Project Open House operates as follows. An occupational therapist evaluates both structure dwelling and client needs; this information is used as a basis for the prescription of structural modifications and equipment that will allow increased physical accessibility. On completion of the prescribed work, the therapist trains the individual and family in the use of the modifications. Project Open House and Family Support Services are community programs that provide a cost-effective method for improving the quality of life for disabled individuals and their families.

Several years ago, members of a parents' group at United Cerebral Palsy of New York City, Inc. (UCP/NYC) began to describe the difficulties in caring for their developmentally disabled children at home. The lack of accessible housing often left institutionalization as the only viable solution. The group reviewed alternatives, and the concept of a program to modify existing housing for architectural accessibility was born. The search began for sources of financial backing for such a program.

It was determined that the source of funding might be public agencies serving either or both housing and social service needs. It was hypothesized that capital improvements (the elimination of architectural barriers) might end public expenditures for social services (home attendant care) and, possibly, income subsidy.

In 1974, Congress, through the Housing and Community Development Act, established the Community Development (CD) Block Grant Program. The CD Block Grant program provides housing, economic development, neighborhood facilities and public services that benefit low and moderate income persons. This was the program through which UCP/NYC received its funding, based on the agreement that UCP/NYC would meet all overhead costs.

In 1980, a pilot program, Project Open House (POH), began as a cooperative effort between UCP/NYC, The New York City Mayor's Office for the Handicapped, and the Department of Housing Preservation and Development. Because of its federal funding, POH was obligated to extend its patient group beyond the developmentally disabled to serve a varied disability group. The needs of the developmentally disabled were easily generalized to the needs of disabled New Yorkers as a whole, those individuals whose mobility was impaired because of trauma, disease, or the aging process.

Individuals who suffer a disabling accident or disease will often undergo many hours of therapy in a hospital or rehabilitation facility. However, when they return home, they may find that they cannot get their wheelchairs through narrow bathroom doors or they cannot enter and exit their homes independently because of entrance stairs. When POH first began, the New York City Mayor's Office of the Handicapped estimated that 380,000 disabled individuals (i.e., ~5% of the population) lived in the city. Yet, only 1% of the housing in New York was designed for special accessibility needs. These special needs, along with other difficulties that the dis-

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abled and their families face, are addressed by POH and are described below.

Role of the Occupational Therapist
“Occupational Therapy’s fundamental concern is the capacity, throughout the life span, to perform with satisfaction to self and others those tasks and roles essential to productive living and to the mastery of self and environment” (1, p 204).

An occupational therapist was chosen as the health professional best trained to enter an individual’s home, assess the individual’s level of functioning and the structure within which the individual lives, and create plans to modify the home for increased accessibility. Thus, this adapted environment allows these individuals to function independently at their maximal capacity and assists the individual’s caretakers in providing safe follow-through in activities of daily living (ADL) skills.

The role of the occupational therapist within the POH framework was designed to complement the more traditional role of the therapist in home care. Thus, with architectural barriers removed, the disabled individual can benefit fully from a home care program of both therapeutic and ADL (homemaking, personal hygiene, grooming, and recreation) activities.

Outreach
Locating eligible program participants was achieved several different ways. At the inception of POH, letters introducing the program services were sent to all the major service agencies in New York City, including but not limited to the Muscular Dystrophy Association, the Arthritis Foundation, the Multiple Sclerosis Society, Easter Seals, stroke clubs, and hospitals. Public service announcements were sent to radio news stations and television stations. However, to a large extent disabled people exist as an isolated group in the community. Often, these individuals do not know how to gain access to the various community services and programs open to them. Also, poor communication between agencies and departments within an agency slowed the dispersal of information. The results of the first year of publicity came in slowly.

Because of the delays of outreach, it took POH two years to complete the quota of patients funded by its first CD grant. In 1982, a social worker was added to the POH staff, and she began a more systematic outreach. She was able to establish a personal rapport with individuals at various service agencies. Consequently, the number of applicants for POH began to grow. Project Open House soon gained an established position in the city service network and had referrals from health workers, agencies, and patients.

Recent cutbacks in the provision of other services, including hours of home attendant care and changing demographics in favor of the aging, have contributed to the growing need for home modification services. To date, POH has a waiting list of needy patients, with referrals coming from many private and institutional sources.

Staff Development and the Evaluation Process
The mobility-impaired patients served by POH span a wide range of disability severities, age groups, and diagnoses, including but not limited to spinal cord injury, cerebrovascular accident, multiple sclerosis, cerebral palsy, amputation, mental retardation and developmental disabilities, spina bifida, and arthritis. Both the evaluation tools and the staff must be versatile, so that the most beneficial modifications for the patient, family, and helpers can be determined.

The original staff consisted of a part-time director, a full-time occupational therapist, and a project manager; the project manager supervised the technical aspect of home modifications. Structural work was completed by outside workers. The original list of modifications that POH was required to make consisted of 12 items, including the installation of grab bars, small ramps, and emergency equipment; the widening of doorways; and the lowering of kitchen cabinets.

Although a small modification often made a big difference in increasing a patient’s level of independence, it became apparent that the scope of problems POH was addressing was more complex than first believed. By the third funding year of POH, a core staff was developed to help the multifaceted needs of its patients.

The program director supervises the staff, operations, and financial matters related to the project; does outreach, public relations, and reporting; and must adhere to contract and budget terms. The occupational therapist acts as the accessibility specialist. He or she visits the patient’s home, evaluates the patient’s functional level, and assesses architectural barriers in the home. He or she then draws up plans for modifications to achieve optimal therapeutic outcome and
provides follow-up training. On request of the occupational therapist, the technical consultant visits sites and evaluates the structural feasibility of the occupational therapist’s plan. He or she then draws up the technical plans specifying exactly how the work is to be done. The administrative assistant answers phone inquiries, types, purchases equipment, and processes other office paperwork (e.g., billing, contracts). Because the modifications become increasingly complex, the work was subcontracted out to individual general contractors; a competitive bidding process was implemented to limit costs.

When a person enters a disabled individual’s home to alter the living space, he or she must consider emotional, social, physical, and structural aspects of the living arrangement. Thus, in 1982, as POH began its second year of funding (third year of operation), a social worker was hired. This social worker speaks with the individual or other family members, prior to the home visit to gather general background information for the therapist’s evaluation. By accompanying the therapist on home visits, the social worker can lend his or her expertise to facilitate positive family dynamics and to counsel the individual and family to reach a satisfactory home modification plan. He or she also acts as a source of information and referral, educating the family regarding other sources of services available to them in an effort to integrate them more fully into the community.

**Occupational Therapy Evaluation Tool**

Initially, the patient’s primary therapist or treatment team described the home modifications. This system, however, had the following two major weaknesses: a) it was difficult to coordinate the opinions (often conflicting) of the many different individuals involved in patient care; and b) many professionals in the rehabilitation field were not sufficiently familiar with accessible design or adaptive equipment to make the appropriate recommendations. Therefore, it was concluded that as much information as possible had to be gathered in the home by POH’s occupational therapist and social worker, with the primary treatment team acting as a source of verification of POH’s findings.

An evaluation form, the result of several revisions of tools, was designed to gather information systematically for architectural barrier removal (copies may be obtained by sending $1.50 to Project Open House, UCP Housing Services, 105 Madison Avenue, New York, NY 10016). Observations are made of the patient’s functional ability, extent of disability, and prognosis. The patient’s level of independence and the availability of helpers in various areas of ADL are noted. As much quantitative information as possible is taken when on location. The entrance and exit to the home and each room and hallway are measured and assessed for accessibility. Safety factors and means of summoning assistance in the event of an emergency are noted.

The process of evaluation is a dynamic one, with patient and family involved throughout. The patient demonstrates needs and abilities; furthermore, the patient and family members are encouraged to voice their preferences and priorities in terms of how POH money will be spent.

**Modifications**

The number of acceptable modifications provided by POH has grown from 12 to more than 58. Although guidelines for modifications can be listed, each family, patient, and home structure provides a unique challenge for the occupational therapist in designing the combination of modifications and equipment most beneficial to all. Originally, costs of such alterations frequently exceeded the established ceilings for expenditures per individual. For this reason, UCP/NYC agreed to match costs for contractual services at a 20% level.

The choice of modifications presented to the family is a result of a prioritization of basic home health and safety needs that are within the limits of the POH grant budget. Ultimately, however, the patient and family decide which needs are most critical. Only in a case where the occupational therapist’s professional judgment determines that the family’s wishes are contraindicated for the well-being of the disabled individual will those wishes be denied. In all cases, consultation is made with the primary therapy team and physician.

Generally, modifications are made in accordance with the guidelines established by the American National Standards Institute (ANSI) (A117.1-1980). These standards are based on physical measurements of the average adult male. Clearly, these standards will not best serve those disabled individuals who vary greatly from the average, such as the developmentally disabled or frail elderly population. Professional judgment is therefore used in adapting standards to meet individual needs. In addition, the
modifications that POH provides are superimposed on an already-existing structure that may not allow for optimal modifications. Once again, the therapist's professional judgment is called on to design modification or equipment alternatives that most closely follow the ANSI guidelines and meet the patient's needs.

The following are the modifications most often requested by patients to address the needs most basic to ADLs.

Stairways. The difficulty of stairway access is addressed as follows. When the height of the stairs and adjacent property allows, a ramp is constructed according to the ANSI guidelines. When such a ramp is not feasible, or if the stairs are interior, POH helps provide one of several types of mechanical lifting devices designed to take disabled individuals up and down stairs. Unfortunately, these devices are often costly and exceed the POH budget; often POH funds are matched by the family or benevolent organizations.

Doorways. The widening of doorways to accommodate the passage of a wheelchair can usually be accomplished quite simply. However, when structural considerations do not allow such a modification, equipment alternatives are suggested. These include the use of a narrow-rolling (or commode) chair, the use of “swing clear” hinges, or replacement of the door by a curtain.

Bathrooms. Bathroom modifications may be as simple as a few strategically placed grab bars beside the tub or toilet; these enhance safety in sitting balance or independent transferring for bathing and toileting. Tub seats and hand-held shower devices may be added for additional ease and safety. In a more complex case, removal of a tub may be necessary to allow the construction of a roll-in shower area level with the bathroom floor surface. Such a modification allows the patient to be rolled into the shower, thus eliminating the often dangerous transfer in the bathroom. If funds and house structure allow, a bathroom can be expanded or a new bathroom may be provided in a more accessible part of the house (e.g., first floor rather than second floor). To allow for maximal independence in self-care, items such as accessible “roll under” sinks, lever-blade handles, and tilt mirrors may be installed.

Meal Preparation. For those patients responsible for their own or family's meal preparation, countertop burners, wheelchair height ovens, accessible sinks, counter-space, and storage space may be provided. When appropriate, adaptive equipment for meal preparation and eating, such as utensils with built-up handles, a one-handed chopping board, a rocker knife, and plate guard, are purchased.

Bedroom. In the bedroom, closed rods may be lowered to within wheelchair reach. Windows may be replaced by those that may be more easily opened and shut by a person in a wheelchair or by someone with decreased strength or coordination. Bed rails may be provided to assist someone in pulling up to sit in bed. Developmentally disabled patients have benefited from innovative sleeping or recreational environments designed by POH staff. For example, a wheelchair-height platform bed (4 ft x 8 ft) was designed to incorporate two-foot and four-foot solid removable sides at its periphery. All surfaces of the bed and sides are padded and are covered by inflammable carpet material. An inflammable, treated mattress fits the inside surface of the bed. This creates a sleeping, playing, feeding, and dressing environment for a multihandicapped child.

For each patient, various safety factors are evaluated and addressed. These may include the provision of smoke alarms, adapted phone equipment, emergency buzzers, which can summon assistance up to 200 ft away, and wheelchair-accessible peepholes and locks at the front door.

Modifications usually just enhance an individual's current living situation; however, the occupational therapist may suggest options that can lead to changes in total lifestyle. Such a change occurred in a family with an adult son John (fictional name) who had spina bifida. John had good upper extremity strength and was independent in ADL and for propulsion of his wheelchair. John's family lived in a private home that had a short flight of stairs at its entrance; this necessitated that John be carried up and down the stairs to enter and exit the home. Project Open House was called in to modify these stairs. The occupational therapist determined that the structure of the home would not, under the limits of the POH budget, allow for modification of these stairs. However, she did discover a ground-floor apartment in the home that had a separate entrance at street level but that lacked a wheelchair accessible bathroom (see Figure 1). Thus, to offer wheelchair access (see Figure 2), POH was able to remove a tub, add a stall shower, turn a toilet 90°, and widen a doorway. With counseling and encouragement, the
family allowed John to move downstairs to these independent living quarters, with the expectation that the family would carry him upstairs to be with them on weekends. However, John enjoyed his new space and freedom so much that he ultimately preferred entertaining friends and family in his own apartment on weekends rather than going upstairs.

Release Forms
Once a decision is made as to the modifications and equipment desired, a document, in the form of a release, is signed by the patient or family. A similar release form must be signed by the landlord when the structure of the building is being altered. Initially, it was thought that this form would be an obstacle to work completion. However, in reality only 20% of the landlords have had any objection to the work. After advocacy for the cause by the POH staff, however, only about 3% of the landlords refused the modifications.

Treatment and Training
After modifications are finished, the occupational therapist returns to the home to inspect the completed work. He or she verifies that the work meets the specifications of the plans. The therapist then spends as many additional sessions as necessary to ascertain the patient’s safety in using the modifications and equipment. Thus, the therapist is often called on for transfer training, or treatment in various aspects of ADL, including homemaking, meal preparation, eating, and grooming. If the patient is followed by a therapist either in the home or on an outpatient basis, this training is done in consultation with the primary therapist. A referral for ongoing therapy is made if it appears that the patient may benefit from long-term or more intensive occupational therapy in the home or clinic.

Family Support Services and the Future
During POH’s fourth year, the staff was expanded: the occupational therapist working with the program assumed responsibilities of director, a second occupational therapist was added, and a nurse was hired to assist in the social service aspect of the program and to add her expertise in health education and maintenance. As a result of the POH experience, UCP/NYC established a program known as Family Support Services (FSS) to provide services that might better integrate mobility-impaired individuals into their communities. Thus, as the evaluative and treatment roles of both the social worker and nurse expanded in the field, a case aide was added to the staff to handle information and referral within the office.

Although targeted originally as needing architectural barrier removal, the disabled population served by POH was found to have many other far-reaching needs. Many disabled New Yorkers live isolated in their homes, not knowing where to turn for support and services. An example of such a person is Mr. J. Mr. J. was close to completing art school when he suffered a spinal cord injury that left him with a T4 paraplegia. Although he was independent in self-care, Mr. J. remained a prisoner in his home because of several steps at the entrance of his dwelling. In addition, he had conflicting feelings about being paraplegic that had never been addressed. Furthermore, he had never had the opportunity to ben-
efit from vocational training services. Through POH, a ramp was built at the entrance to his home. Through FSS, he was referred to an outpatient rehabilitation program where he currently receives group and individual counseling along with vocational assessment and training. Soon he will begin training in art restoration techniques.

POH, FSS, and Cost Effectiveness

Through POH, a one-time expenditure of $1,000 (on average) has been found to make the difference between an individual remaining at home and being institutionalized, at costs of up to $128,000/individual per year. Often, subsidized home attendant care costs may be decreased as well. Family Support Services is particularly effective because it provides a single point of entry into the service network. Furthermore, the transdisciplinary approach used by the project provides for continuity of services for all project participants. The case management allowed through FSS enhances the quality of and satisfaction with the modifications provided. Additionally, the low middle income group, for whom paying for services is most difficult, can be provided with many of the modifications and support services they so badly need.

Conclusion

An independent evaluation of POH's first grant year, made by a Columbia University professor, reports that 85% of the disabled service recipients stated that the modifications changed their lives for the better (2). Many recipients said that their feelings of independence and safety were enhanced. Also, the program is of great value to other household members. It is striking to note that 75% of the household members stated that the modifications also changed their lives for the better. Project Open House continues to monitor patient satisfaction by sending a questionnaire to each patient several months after the modifications are completed. Periodically, phone calls are placed to recipients to assess their satisfaction with previous modifications and to discuss their need, for additional work if funding allows. This is particularly critical in situations where patients have progressive disabilities.

Project Open House and Family Support Services are dynamic programs directed at the elimination of physical, psychological, and social barriers to the independence of disabled individuals in their communities.

REFERENCES


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