ENABLING ENVIRONMENTS: PEOPLE, WHEELCHAIRS AND STANDARDS

by

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ABSTRACT

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Submitted to the Department of Architecture in June 1980, in partial fulfillment of the requirements for a Masters of Architecture in Advanced Studies.

Designing environments to accommodate people in wheelchairs is far more than ramps and wide toilet stalls built according to the state building code. This study attempts to illuminate the functional imperatives behind certain standards (especially relating to spinal cord injuries) and to show how families with chair-bound members actually use their homes.

There are seven case studies in the body of this work ranging from a situation where both parents are disabled to the typical nuclear family with only one disabled parent to 'families' composed of unrelated individuals sharing a home. Use of each house is illustrated via a diary-generated daily routine as well as by a house evaluation showing the adapted and unadapted features. The case studies are heavily illustrated with photographs.

The final chapters discuss the issues and themes that emerged from the study and propose a model of individual competence that is based on an equilibrium among various options for adapting behavior and/or physical surroundings. Prioritized standards are proposed, parallel to ANSI A117.1-1977, that advocate broad application of minimum accessibility standards, narrower application of acceptable accessibility standards and specialized application of adaptive accessibility standards. This proposal is made in order that a wider range of housing choices be made available to families with chair-bound member(s). In general it was found that most requirements for accessibility did not interfere with the needs of the ambulatory - except in the requirements for counter heights in the kitchen.

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The photographs owe much of their quality to the sound advice from Harold Lewis and the flash equipment he was so kind as to loan to me. Thanks are also in order to Dr Howell and to Star Ockenga for starting their photodocumentation course at exactly the right time for me.

Moral support in the final push of production has come to be one of the most valuable of commodities. Many, many thanks to my parents, Mae and Forest Pecht, for their continued support; to Lynne Gay for editing and numerous pep talks; to Barbara Mehren for the extra mothering I needed; and to my daughter Stephanie for pulling out of her teenage doldrums just in time.

Many of the participants in this study have become my friends - far beyond the call of duty in being part of an academic study. To all of them I owe my thanks for their openness and assistance. Special thanks are extended to Tip and Patricia Thiboutot for their immense contributions as contact, pilot and friends.
DEDICATION
To the study participants, who invited me into their homes and shared a bit of their lives with me. My thanks for making it possible.
Introduction

This study was undertaken for many reasons, not the least of which was a curiosity about the sorts of information that most readily inform design and make a contribution toward improving our environment. It seems that evaluating existing environments and documenting the ways they are used has a great potential for serving this information function. Post occupancy evaluations (POE) have most often been conducted in housing environments, especially public housing. Since the passage of federal and state legislation mandating that all new construction and major renovations using public monies must be accessible to people, regardless of their physical disabilities, there has been a mounting tide of guidelines and standards for the design of barrier-free environments. There is still no nationally accepted standard that applies to housing. There has been very little POE literature that addresses the issues of housing for families with one or more members with mobility impairments. Ostrander, in a study for HUD, published one of the first POE's of a congregate setting for quadraplegics. The American Society of Landscape Architects Foundation has evaluated sites for congregate housing and a number of parks and other outdoor public places. Lifchez's book, while not a POE, has done an excellent job of demystifying the realities of independent living for those confined to wheelchairs. His analysis is in terms of the intimate environment, the dwelling environment and the community environment. Fottt's work is one of the few attempts at a design guidelines book that includes family issues. Much of the POE work has dealt with issues of preference and satisfaction. This information is useful to designers in terms of marketable design features yet it does little to inform them about the full range of activities and meanings that need to be supported by the home environment. Other studies have raised issues of major importance for design. Cooper has documented the importance of the relationship of outdoor space to family activities. Festinger's work showed the impact of site design on friendship formation. The work of Beck, et al carefully notes...
the requirements for both indoor and outdoor spaces for Canadian low-rise housing. Howell has documented the use of private and public spaces in congregate housing for the elderly. What is needed is a systematic continuation of this work to document variously constituted family groups, how they use their homes and how their physical surrounds support or inhibit their activities.

The design of the physical environment for a person confined to a wheelchair can mean the difference between independence and dependence, between gainful employment and inactivity. Norris-Baker has documented a dramatic increase in two people's ability to negotiate their home environments when they moved from unadapted residences to adapted ones. Most of the research behind standards and guidelines has been based on the anthropometrics of individuals, their specific disabilities and their use of wheelchairs and other adaptive equipment. There has been no analysis of the residential standards as used by families in their actual home environments. This study is an attempt to begin some of that work by presenting seven case studies of families and their homes.

INCIDENCE

"No one really knows how many handicapped people there are in the United States; this in itself is a strong indication of their invisibility." A recent (un-dated flyer by the Paralyzed Veterans of America (PVA) estimates that there are over 200,000 paralized Americans and that their numbers are growing at a rate of 10,000 per year. At this rate, by the year 2000, there will be over 400,000 people in the US confined to wheelchairs. These figures represent an estimated 1% of the total population; 10% of the total disabled population.

Much of the difficulty in developing accurate statistics is due to the fact that different agencies define disability in different ways. The census is developed from self-reports of disability, the Department of Labor defines disability as any impairment that prevents a person from working or from doing their regular job. There is no central information collection agency that records the incidence of impairments by type, so that the best statistics available to any agency is at best an estimate. In addition, there is no way to gather accurate information on the number of people who are temporarily disabled.
ASSUMPTIONS

This study is based on a number of assumptions about what makes up a good environment for people who are chair-bound. The basic assumption is that maximum independence within the limits of one's disability is the basic goal. A second assumption is that one's home should not have an institutional look about it and should reflect one's personality rather than one's physical limitations. The home environment should be both physically and psychologically enabling.

There is no single set of housing solutions for the chair-bound population; maximum choice is the ideal.
FOOTNOTES


8. Festinger, Leon, SOCIAL PRESSURE IN INFORMAL GROUPS, Harper & Bros, N Y, 1950


Directions of Inquiry

While it may have been useful to offer a general description of behavior/environment interactions, there were a number of more specific questions that helped to shape this investigation: What is the relationship between the level of spinal cord injury and the need for the home environment to be adapted? What is the need for able-bodied family members to adapt their behavior? What is the interaction between an adapted home and adapted behavior? Lawton and Nahemow's transactional model of environment/behavior interactions seems relevant to this thread of inquiry. The components of this model include:

1. **Degree of individual competence**: a collection of abilities that may vary over time including cognitive ability, psychological adjustment, physical health and so on.

2. **Environmental press**: forces in the environment that demand a response. The positive or negative value of press is defined by the individual and will vary with changes in the environment and with an individual's competence.

3. **Adaptive behavior**: one result of the individual/environment transaction. Adaptation is defined by social norms and individual values for self actualization.

4. **Affective response**: internal emotional states including emotional and evaluative attitudes.

5. **Adaptation level**: the state of competence and environmental press being in equilibrium, including affective, perceptual and cognitive aspects.

The zone of maximum performance is found to the right of the AL (adaptation level line) at an environmental press level which is greater than the adaptation level.  

Home environments serve as continuing rehabilitation...
centers as well as a support system for the person with a spinal cord injury. In order to promote maximally adaptive behavior it seems logical to expect that people confined to wheelchairs will choose environments that are closer to their maximum performance levels than to their adaptation levels. This is congruent with the goal of normalization - meaning the goal to allow the disabled individual to be as autonomous and as near "normal" functioning as possible with the least amount of assistance by others. Therefore, normalization, for people with mobility impairments, may mean the fewest possible adaptations to their physical environments and the fewest adaptations in the behavior of other family members. Verification of this concept seems to be a logical line of inquiry for these case studies.

Another related set of questions concerns the level of family support required by the member with a disability: Are the caretaker/provider roles reversed or reinforced or unchanged? Do the physical adaptations that families make reflect their role implementations? Are there any unique design issues that arise from a study of families with a chair-bound member as opposed to studies of individuals?

A third series of questions emerged from the apparent tension between the goal for adapting the environment to allow for independence and the goal for normalcy: How important is "image" as a factor in making decisions to adapt or not adapt? Is resale value an important consideration? What are the most important factors that lead to the current choice of a home? In making adaptations and in choosing furniture and equipment are factors such as increasing or decreasing adaptation levels considered?

A fourth set of questions surrounds the existing guidelines and standards: Would not performance standards be far more useful to designers than the specification-type standard? Are some of the standards more appropriate or less appropriate for families? Should standards be written with priorities in mind rather than as if all elements were of equal import?

The final set of questions is related to the amount of space required: Do families feel they need more space or show evidence that they buy less furniture to accommodate the
mobility needs of the chair-bound member? If so, what are the priority activities?

Spinal Cord Injury

It is important for designers to understand the 'why' behind design imperatives so that their buildings are thoughtfully functional rather than non-functional through blind adherence to codes and standards. The following discussion of the physiological consequences of spinal cord injury are to help contribute to that understanding.

A severed spinal cord results in the loss of motor function and sensation below the level of the injury. In designating the level of injury, the letter indicates the area of the spine involved (C = cervical, T = thoracic, L = lumbar, S = sacral) and the number indicates the order of the nerve or vertebra counting from the head down. Thus, T1 is the thoracic vertebra or nerve closest to the head. For clarity in discussing levels of injury, these designations will signify that the spinal nerve at that level is intact and that the cord is completely severed below that level. In reality, many injuries result in an incomplete severing of the spinal cord so that a wide range of combination of function is possible. One example is "upside-down" quadriplegia which results from a partially severed cord in the cervical region. The more interior nerves that serve the lower part of the body are not completely damaged so that some motor function and sensation remain while there is no use of the arms. The figure below shows the relationship of the spinal cord to a cervical vertebra.

Figure 2. from Hoppenfeld, p40.

Figure 3 shows the different levels of motor function associated with the spinal nerves. The diagram is schematic because the domains of the nerves
SCHEMATIC DIAGRAM OF MUSCLE AREAS CONTROLLED BY EACH SPINAL NERVE

Figure 3.
overlap and cannot be shown explicitly in one diagram. Stanley Hoppenfeld has clearly outlined the levels of motor function and sensation in his book *ORTHOPAEDIC NEUROLOGY.*

<table>
<thead>
<tr>
<th>Level</th>
<th>Motor Function</th>
<th>Sensation</th>
</tr>
</thead>
<tbody>
<tr>
<td>C1-3</td>
<td>No use of arms or legs</td>
<td>Breathing with a respirator</td>
</tr>
<tr>
<td></td>
<td>Sensation: None below armpits</td>
<td></td>
</tr>
<tr>
<td>C4</td>
<td>Independent breathing with low respiratory reserves</td>
<td>Can shrug shoulders</td>
</tr>
<tr>
<td></td>
<td>Sensation: Includes upper shoulders and upper chest.</td>
<td></td>
</tr>
<tr>
<td>C5</td>
<td>Shoulder and some upper arm muscles function, limited elbow motion, few can propel manual chair.</td>
<td>Present above elbow.</td>
</tr>
<tr>
<td>C6</td>
<td>Full function of shoulder, bend elbow, flex wrist, respiratory reserve low, can propel manual chair.</td>
<td>Present in the outside of the arm to the thumb, index finger and part of the middle finger.</td>
</tr>
<tr>
<td>C7</td>
<td>Can extend fingers, grip very weak.</td>
<td>Present in the arm except for the inner arm between elbow and armpit.</td>
</tr>
<tr>
<td>C8</td>
<td>Pinch mechanism of the thumb to index finger and middle finger OK, grip is difficult.</td>
<td>Present above elbow.</td>
</tr>
<tr>
<td>T1</td>
<td>Arms fully functional, trunk stability absent, cannot spread fingers.</td>
<td>Present in arm except for armpit.</td>
</tr>
<tr>
<td>T2-5</td>
<td>No useful trunk balance.</td>
<td>Present in upper chest and back.</td>
</tr>
<tr>
<td>T6-10</td>
<td>Some trunk balance, not full strength.</td>
<td>Present on the inside of leg and foot.</td>
</tr>
</tbody>
</table>

(Note: There are only seven cervical vertebrae and eight cervical nerves. Both C7 and C8 exit the spine between the C7 and T1 vertebrae.)

<table>
<thead>
<tr>
<th>Level</th>
<th>Motor Function</th>
<th>Sensation</th>
</tr>
</thead>
<tbody>
<tr>
<td>T11-12</td>
<td>Good trunk balance</td>
<td>Present between waist and upper chest.</td>
</tr>
<tr>
<td></td>
<td>No use of legs.</td>
<td></td>
</tr>
<tr>
<td>L1</td>
<td>Some hip muscles operable.</td>
<td>Present above groin.</td>
</tr>
<tr>
<td>L2</td>
<td>Can flex hip.</td>
<td>Present above mid thigh.</td>
</tr>
<tr>
<td>L3</td>
<td>Weak control of front thigh muscles, no real control of knee.</td>
<td>Present above knee.</td>
</tr>
<tr>
<td>L4</td>
<td>Normal use of front thigh muscles, can extend leg, partial movement of big toe.</td>
<td>Present in upper chest and back.</td>
</tr>
<tr>
<td>L5</td>
<td>Partial ability to flex knee, hip function poor due to loss of function in back thigh and buttocks muscles.</td>
<td>Present in upper chest and back.</td>
</tr>
</tbody>
</table>
Sensation: normal in leg except for outside and bottom of foot.
S1=Motor: hip and knee normal, toes very weak, no voluntary control of bladder or bowels.
Sensation: normal in legs except for saddle area.
S2=Motor: toes are weak, some bladder and bowel control.
Sensation: crotch is numb.
S3-5=Motor: toes are normal, bowel and bladder functions are present.
Sensation: S3 controls most genital sensation, S4 the ring around the anus, S5 controls anal sensation.

INCONTINENCE
With a complete injury, para- or quadraplegics lack bowel and bladder control yet are able to compensate by regular elimination habits and by internal or external catheters. Once a person has developed a regular schedule, there are very few accidents, but the accessibility of the toilet may mean the difference between embarrassment and normalcy. The use of catheters and portable urinals increases the amount of time needed for elimination as well as increasing the need for privacy.

Bones that are not stressed by walking or other muscle tension tend to lose their mineral content. These minerals are passed out of the body in the urine. This fact, plus the need to avoid constipation, means that chair-bound people need to drink far more water than walking people so that access to drinking water is not a luxury, but a necessity.

TEMPERATURE SENSITIVITY
Another consequence of spinal cord injury is the loss of function of portions of the autonomic nervous system. Most important for design consideration is the loss of the thermal regulation system. The result is that the body overreacts to changes in temperature, becoming chilled in cold weather and overheated in hot weather. The tolerance for temperature change is thus much reduced.

TRANSFERS
The term transfer is used to denote the operation necessary for moving from wheelchair to bed, tub, toilet or other place or from any of these places to the wheelchair. Sara Harkness, in BUILDING WITHOUT BARRIERS, illustrates the different types of transfers.

People with injuries above C5 are unable to make transfers.
independently. Many with C6 level injuries are able to transfer from bed to chair, etc. without help though it takes a good bit of time due to the lack of strength and the percentage of the body that must be lifted by the few working muscles. The lower the level of injury, the greater the ease of transfer. Paraplegics have full use of arm and shoulder muscles and thus have little trouble learning to make safe, fast transfers. The degree of trunk stability present is directly related to the ease of making transfers.

SPASTICITY

Even though the muscles below the level of injury are beyond voluntary control, they sometimes will be subject to spasms. Arm spasms will affect the ability to control an electric chair in a narrow space; leg spasms will affect the time it takes to get dressed or the way a person prefers to make transfers. The potential for muscle spasms creates the need for such things as padded toilet seats and a straight course to the bathroom.

BED AS CONTROL CENTER

With increasing difficulty of transfer, it becomes more important to make an effort to reduce the required number of transfers necessary to carry out the activities of daily living. In order to do this, many quadraplegics make their beds into control centers so that one transfer will be all that is necessary in the evening. Items needed within arms reach may include: water, telephone, light, thermostats, radio, television, reading materials, tissues, clock and medicines.

CHARACTERISTICS OF WHEELCHAIRS

There are two basic types of wheelchairs: manually operated and electrically operated. Manual chairs are powered and steered by pushing on the hand-rims located on the outside of each wheel or by pushing with one foot. Electric chairs are powered by battery and steered by either hand or chin controls. Manual chairs can be put through three basic types of turns: "K" turns, center pivot and wheel pivot. Electric chairs cannot execute the center pivot because

Center Pivot
26" x 40" chair
55"diameter turning circle
that maneuver requires that one wheel rotate forward while the other wheel rotates backward. "K" turns are executed like an automobile making a road turn on a narrow road, moving backward and forward in several arcs until the turn is completed. The dimensions of the required space depend upon the dimensions of the chair and the skill and dexterity of the operator.

Electric wheelchairs are usually larger than manual chairs and may have control boxes on the chair arm that add to the width of the chair. Spokes may be added to the handrims of a manual chair so that a person with no grip can power the chair much like a ship's wheel operates.

Footnotes
Methods

The seven case studies presented here are not statistically representative of the population of people with spinal cord injuries. They were chosen to illustrate the range and variety of family situations that might arise when one or more members of the family are disabled.

CRITERIA

- Families were to have the ability to adapt their homes to meet their needs. Thus, all but one of the case study families own their own homes and the one renting has the potential for making changes.
- As many of the families as possible were to have children in their home or have had children to raise during their period of disability. All but two met this criteria.
- The chairbound family members were to be as evenly divided among men and women as possible. There were six men and two women in the families who volunteered to participate.
- The level of injury among the participants was to vary as widely as possible. The range includes L1 paraplegia to C4 quadraplegia with one participant being post-polio rather than having been injured.
- The ages of the participants range from 24 to 60 and the length of disability ranges from three years to 25 years.
- Only one of the participants requires brief assistance from a person outside the household group and that has been true only for the last year.
- The homes in the study were to be both remodeled and designed specifically to accommodate a chairbound owner. Only one of the homes in this study was designed before construction to meet wheelchair requirements.
- A number of non-nuclear families are included in this study and reflects a growing trend for households to be composed of unrelated members. From 1975 to 1979, 68.8% of the net increase in the number of American households was due to the addition of households of unrelated individuals, 11.5% to husband/wife families and 19.7% to other families.¹

PILOT

Tip Thiboutot and his family served as participants, pilot
case and contact. He suggested a number of people whom he thought would serve the needs of the study and be willing to participate. He also helped to test the interview format, the diary instructions and the photodocumentation schedule.

LETTERS

Letters were sent to all the people who were suggested, asking if they would participate. Those who replied positively were included in the study. Those people who accepted and friends suggested others who might be interested and the list of participants grew slowly but surely. In this way the sample was self-selecting so that anyone who felt any discomfort about talking about the issues raised by the study chose not to participate.

FIRST INTERVIEW

The initial interview was held in the participants' homes and the questions covered the descriptions of each disability, adaptations made to each home, reasons for choosing the house, information sources used in making the adaptations, and the activities that go on in the homes. During this visit a sketch plan was made of each house by pacing off each room and sketching it on graph paper. It is estimated that all room dimensions are accurate within six inches. Participants were also given release forms and diary instructions at this time. (See Appendix for the actual forms.)

DIARIES

In the diaries, each disabled participant and his/her spouse were asked to document five activities: the morning routine from waking up to getting out of the house or into the day's tasks, food preparation/eating/cleaning up after the evening meal, entertaining, caring for children, and being left alone or preparing to leave the chair-bound member alone for a length of time.

SECOND INTERVIEW

The second interview served to discuss the diaries, clear up questions raised in the first interview, correct house plan sketches and to document the families' use of their homes in photographs. In addition to a standard descriptive photograph of each area of the house, the participants were asked to show
any activities, adaptations or problems that they thought might be interesting or useful to others with similar disabilities.

FINAL INTERVIEW

A third interview was conducted with all but two of the participants (one combined the 2nd and 3rd) for the purpose of showing the photograph made of their homes and to ask questions about the themes that seemed to be emerging from the series of cases.

Case Studies
The Thiboutot family is composed of four members: Anna, 9; Michele, 4; Patricia, 38; Tip, 42. Anna has a lively interest in horses and spends much of her time caring for and riding her pony. Michele is an active child who loves her nursery school teacher as much as she loves cookies. Besides managing the household, Patricia participates in a women's crafts store and makes items for sale on consignment. Tip is a prosthetics counselor for the Veterans' Administration and a professor of French Literature for Boston University in the evening program. He also plays basketball often.

Tip was disabled in service when he was 21. His spine was broken at T2 though his spinal cord is probably severed at T4. He has complete use of his arms and shoulders and upper chest muscles with no use of his stomach and lower back muscles. He has poor trunk balance and can turn to reach things behind him at waist height or higher with ease. It is also easy for him to reach things on the floor in front of his chair.

Tip's chair is a sports model that is narrower than the usual 25" rim to rim dimension and has a lower back than other models in order to increase the radius of his reach. He uses a cushion so that the top of the seat is 22½" high. The lack of arms on the chair allows greater freedom in pushing under desks and tables.

WHEELCHAIR DIMENSIONS
DAILY ROUTINE
6am Tip wakes up, transfers to his wheelchair and pushes into the master bath to shave and brush his teeth at the sink. He must approach the sink "sidesaddle" since there is no knee space. He transfers to the shower/commode (waterproof) chair and when he is finished at the toilet, he transfers back to his wheelchair. He then rolls the commode/shower chair into the shower and transfers into the shower. After bathing, he dries himself in the shower chair before transferring back to the wheelchair. He cleans his urinal and external catheter and puts them in place before pushing over to the sink to comb his hair and take his medicines. From here he must turn 180° to get out of the bathroom.

7am Tip pushes to the closet to select his clothes for the day as Patricia awakes and takes her turn at the toilet. She then wakes the two girls and goes to the kitchen to make their breakfast. Tip dresses by laying his clothes on the bed and transferring to the bed to put on underwear, trousers, socks and shoes. If he forgets anything, that means another set of transfers to wheelchair and back to the bed. He then transfers to the wheelchair to put on shirt and tie, gathers up jacket, books and papers and pushes into the kitchen.
Tip drinks a glass of juice pushes through the storage room to the carport, transfers to his car, pulls his wheelchair in after him and is off to work. Patricia makes lunch for Anna and makes sure she has everything ready to leave for school by 7:50am.

After Anna leaves for school, Patricia has her own breakfast and helps Michele get ready for nursery school. She then showers and dresses so that she can drive Michele to school by 9am.

The rest of Patricia's day is filled with a variety of activities inside and outside the house until time to pick up Michele. Anna comes home from school early in the afternoon.

Patricia starts dinner preparations. She removes the ingredients from the refrigerator and takes them to the counter near the stove and sink. Most food preparation is done on the counter. Either Patricia or Anna sets the counter for dinner.

Tip comes home unless he is teaching a class or attending a meeting. The before dinner activity centers around the counter where Patricia is working on dinner, Tip is reading the paper and the girls are watching TV or playing in the family room nearby.

Patricia serves the plates at the counter and the family gathers to eat. Even though the counter is 36" high, Tip finds it comfortable.

Patricia clears the table with help from Anna and the family lingers to finish conversations.
6:45 Tip pushes into the bedroom to prepare lectures or grade papers as Patricia finishes in the kitchen. Michele and Patricia spend time reading or watching TV until Anna joins them after finishing her homework. They might all watch TV or read or play games or work on their separate projects until time for the girls to get washed for bed. The children use the second bathroom that is closest to their bedrooms.

8:30 The girls go to bed and Tip and Patricia have time to themselves until time to go to sleep.

In this household the kitchen/familyroom is the center of household activity which usually involves eating, conversation, TV, reading the paper, reading stories or individual projects worked on in parallel rather than by the whole family. The livingroom is used to entertain guests more formally and is sometimes the site for the girls to play board games undisturbed. The diningroom is also used to entertain more formally and is sometimes the site for projects that must last for a long time or take more space than the counter affords.

CHOOSING THIS HOUSE
With the help of an understanding realtor Patricia surveyed a number of houses. Of the few she selected Tip visited two and found that this house served his needs. After the basic criteria for an accessible entry and bath were met, the major considerations were the modern style and the openness of the interior.
Since becoming disabled, Tip has felt more constrained by small rooms and has a much greater appreciation for open space than before. Other factors that made this house the right one were: initial cost, cost of adaptations, the neighborhood, the covered access to the car and the dead end street which could be used for wheelchair jogging. The major detractor was the narrow hallway and the difficult turns into the front bathroom and into the girls' rooms. These factors are not of necessary to see why one of his daughters might be crying. Otherwise, he rarely uses those rooms.
ADAPTATIONS

The only adaptation to be made before moving day was the construction of the ramp (a) from the carport to the storage room door. Within the next three years, the tub was taken out of the master bath and replaced with a roll-in shower (b). Since the floor is a concrete slab on grade, a slight curb had to be built to insure that water did not flow all over the bathroom floor. This change probably took over 15 minutes off Tip's morning routine by making it easier to transfer in and out.

Also during this time period the sliding glass doors, deck and ramp (c) were added off the master bedroom. This door serves as an emergency exit for all the bedrooms besides the master bedroom. More recently, the driveway has been enlarged and basketball goals (d) installed for Tip's summer and weekend practice sessions.
UNADAPTED ITEMS

Since Patricia is in charge of most of the cooking, the kitchen has never been discussed as an area for adaptation. The narrow hallway and the doors into the children's rooms and into the front bathroom are w/c negotiable if necessary so that the cost of enlarging them is far above the potential benefit. The same is true for the hall closet and the carport storage area. It would be more convenient to have the clothes rod in the master bedroom closet lowered as well as to create knee space and reachable storage space at the bathroom sink, but they have chosen not to make these changes partly due to the expense.

The side deck is accessible from inside the house, but not from the yard. This arrangement works well enough so that there is no pressure to build a ramp at this time. The front entry is not ramped because Tip always uses the carport entry and he can make it down the two shallow steps in case of an emergency. Another reason is that Tip has not thought of a ramped solution that "looks right." This is an interesting comment since his position is that ramps are aesthetically equal to steps. When discussing this issue, he came to the conclusion that there must be some subconscious misfit between his image of a front entry and the appearance of a ramp.

DISCOVERIES

Though most of the guidelines call for a dining surface to be about 30" high (27" clearance), Tip has found that the standard 36" high kitchen counter suits him very well (see p. 23). By leaning on the counter he is able to support himself much
more comfortably than at the lower height recommended. This works so well for him that he is planning to have a desk made at this height in the bedroom where he does his academic work.

SUMMARY

Tip and Patricia's attitude toward adapting their home to suit their lifestyle has been one of trial and error. If they can adapt their behavior easily, then there is little value in remodeling. The major factors influencing the adaptations they have made are: access (ramp from carport), time saving (roll-in shower) and safety (emergency egress from the bedrooms).

Though there are no immediate adaptations planned other than Tip's desk, the most likely ones to be made in the future are: creating knee space under the bathroom sink to cut several more minutes off Tip's morning routine (a), build a ramp off the deck to access the yard and grille (c), build a ramp to the front door (d), and possibly make the carport into a recreation room for the girls and build a larger carport to make w/c to car transfers easier and at the same time create accessible storage. It seems likely that the narrow hallway and the difficult turns into the girls' rooms and into the front bathrooms will remain minor aggravations.
Footnotes

Family 2

FAMILY STRUCTURE

Members of the Fay family are Derick, 12; Fred, 35; and Linda, 32. Derick is a bright youngster whose gang of friends ranges in and out of the house and throughout the neighborhood. Fred is a psychologist who works in the biomedical engineering department at Tufts and Linda is a medical student at Harvard.

DISABILITIES

Fred was disabled in an accident when he was sixteen with resultant C6-7 quadriplegia. He has large muscle control of his arms so that he can bend his wrists, his elbows and shoulders. He has no grip or fine muscle control in his hands. His trunk and neck need support at all times so that he must spend as much of his time as possible in a reclining position. This is due to a recently occurring ascending paralysis that has decreased the strength in his arms and neck.

Fred's chair is battery powered and has hand controls attached to the arm. The control box adds to the width of the chair so that he has to make extra allowance for it when going through doorways. The chair has a higher back than most models so that his neck will be supported when the chair is reclined. When the chair is fully reclined it is 6'-6" long. He uses a 4" thick cushion.

Linda was also disabled when she was sixteen and has T8-12 paraplegia with a spinal fusion between the eighth and twelfth vertebrae. She has normal use of her arms, shoulders and upper trunk muscles. She has virtually no use of the muscles below her waist. She has good trunk balance and can turn to reach things behind her at arm's height and can lean over to reach things on the floor in front of her with little danger of falling.
Linda's chair is the narrowest chair she could find. She has slanted desk arms so that she can push under tables easily. She uses a 2" cushion.
DAILY ROUTINE

During the week Fred stays in town at the Bradford Hotel near his office in order to avoid the long commute while Linda commutes from Danvers to Harvard and Derick goes to the local Jr Hi.

5:30 The alarm goes off and if Linda is awake enough she gets up; if not, she waits til the second alarm goes off at six. If she waits til six she is likely to be late, so she is resigned to 5:30am. She transfers from the bed to her wheelchair, pushes to the bathroom and transfers to the toilet. When she has finished, she transfers back to the wheelchair and turns on the space heater to warm the room in order to take a shower. She then pushes down the hall to wake Derick and then goes to the kitchen to start breakfast, pack her lunch and do last minute chores. When breakfast is ready, she and Derick sit at the diningroom table to eat and talk.

6:45 Linda goes to her office to gather up her books and papers for the day and brings them to the diningroom table. She also picks out her clothes for the day from the office closet and takes them to the bedroom. She then gets undressed, transfers to the shower, showers, dries herself and transfers back to the wheelchair. She mops up any water that has spattered out of the shower. Next she dresses and dries her hair. If necessary, she makes an
additional transfer to the toilet and back to the wheelchair.

7:30 Linda and Derick gather up all their books, lunch, clarinet, etc. Linda turns off the lights, turns down the heat and they go out to the car where Linda transfers into the car, packs in her w/c and is off to drop Derick at school and go on to her own classes.

5pm While her schedule varies, Linda is usually home in the

TYPICAL WEEKEND DINNER
late afternoon so that she can have dinner ready by 6pm or 6:30. She pushes back and forth between refrigerator, sink and stove, carrying things on her lap or on a tea cart. Dinner is usually served from the tea cart in the livingroom in front of the TV, but sometimes they use the dining table. The cart is then loaded up with dirty dishes and pushed back into the kitchen so that the dishes can be rinsed and put into the dishwasher.

7pm While there is no set evening routine, most nights are full of studying for both Linda and Derick. They might watch TV or work on current projects or chores. Derick might also visit a friend or have someone over.

On the weekends Fred is home and the schedule takes on a different structure. Everyone sleeps later and for about an hour a home health aid comes to assist Fred with his morning routine. She gives him a bedbath and helps him to dress and to make the transfer from bed to wheelchair with the aid of a sliding board, basically the same routine as at the Bradford. He then drives into the bathroom to brush his teeth and to finish the rest of his morning toilet.

Family activities center in the livingroom and diningroom. When Linda can be pulled away from her books and Derick is not out playing with his friends, the three of them play cards or strategy games on the diningroom table. Eating, watching TV and playing music (both instruments and stereo) are the major livingroom activities. If the weather is nice, they may eat out on the back patio, carrying the food to the livingroom window on the tea-cart and passing it out to the table just below the window. When entertaining outdoors, the cart makes short work of all the
carrying that needs to be done. Linda takes charge of the food, Fred takes charge of the music and if the party is large enough they hire a maid to come the next day to clean up.

Often on weekend evenings Fred and Derick will go to the bedroom for several hours to play a new strategy game that Derick has devised. It is easier for Fred to play lying down than when partially reclined in his chair. He can transfer from the chair to the bed with Linda's or Derick's help and undressing is far easier than dressing so that the home health aid does not need to return in the evening.

CHOOSING THIS HOUSE

They chose their neighborhood because they had heard about it from a disabled friend and because they discovered the area was flatter than most nearby towns. It was also close to Lynne, where Fred worked at the time. Another factor was that there were good schools in the area. The same friend alerted them to the potential accessibility of the "Campanelli Ranch House". It seems that the developers designed their models to be basically accessible by accident. The Fays were able to find a "Campanelli" in the neighborhood they liked, so they moved in 1974. The major detractor to the house at this point in time is that their job destinations have changed and the long commute to Boston is arduous enough to make them consider moving in the near future.
HOUSE EVALUATION 2

ADAPTATIONS

All that was required for the Fays to move in to their "Camp-anelli Ranch" house was a ramp (a) from the garage to what was then the recreation room. They also took the automatic door closers off the screen doors. Within two months they had put in permanent ramps to the front and back doors and installed a string/latch system for closing the doors behind them on the way through. (b) They also lowered the mailbox. Within the next six months they had the oil tank (c)
moved out of the garage to give more space for making wheelchair to car transfers. At this time they also widened the garage door and installed an automatic door opener.

Two years after moving in they took the doors off the kitchen cabinets under the sink and had a relative saw out the cabinet bottom (d) so that Linda could roll under the sink. During this break the tiles around the tub.

About four years after moving in they abandoned the built-in refrigerator (see photo "b" on p.38) for an upright refrigerator (g) that was easier to use.

Shortly after moving they added a tilted mirror to the masterbath medicine cabinet mirror. Three years after moving in they remodeled the bath and closet to provide an accessible shower and removed the wall and door to the toilet and sink (f). The use of the shower bench in the other bathroom had a tendency to

Fred had the recreation room divided into an office for his private consulting practice (e) and a storage room.

Their bed (h) was specially made for them by a relative so that it is the correct height for making transfers to and from
the wheelchairs. The supports are indented to allow the chair footrests to pass by and there is rolling storage underneath. It also has a headboard shelf that allows Fred to make the bed into his control center. He has also had a mirror installed on the ceiling so that he can see the position of his legs when he is in the bed.

Much of their storage space is open shelving with a maximum height of 5' so that either Fred or Linda can reach every item. Much of the upper kitchen cabinet storage is unused because it is out of reach even with a "store-keeper's helper". The most used piece of furniture is the teacart used to carry things from the kitchen to the other rooms and back. The major criterion for choosing other furniture is whether the handles and drawers are easy to operate.
**UNADAPTED ITEMS**

Linda finds that the standard height (36" to the bottom) oven is appropriate for her use, yet the range top at the same height is useable but awkward. She cannot see into the pots on the burners.

They have chosen not to widen all the doors since they can get through them with little or no difficulty. They did not provide an emergency exit from the master bedroom because they felt that it was too expensive.

**DISCOVERIES**

They discovered that by removing the closet doors and using open shelves that many of their storage problems were solved. They also found that overhead lights are a major problem when it comes time to change burned-out light bulbs. The pull-down lamp over the dining room table is a pleasant contrast. They also found that the raised hearth of the fireplace made it possible for them to use it easily.

The double-hung windows are impossible for either of them to operate so that they have to ask their son to open/close the windows.

**SUMMARY**

Both Fred and Linda went to college at the University of Illinois in the Rehabilitation Education Center which is directed by Tim Nugent. The
program was independence oriented and focused on developing abilities to function without having to depend upon a particular piece of equipment. Their home reflects this philosophy in that there is a minimum of equipment and their most useful items are as ordinary as possible without being too individualized.

There are no renovations planned for the future but Fred would like to add solar heating capacity. Linda would someday like to renovate the kitchen yet is hesitant due to the expense and the potential impact on resale value. Items that they list as ideal include: maintenance-free exterior cladding, a heated driveway and a screened-in porch where the patio is now.
Family 3

FAMILY STRUCTURE

Henry David (a pseudonym) is 26 and bought his house with a friend. His household is in the study because it reflects a growing trend of single people sharing a house for the economic advantages it provides. The members of their household includes their girlfriends and a couple of housemates. Henry is an undergraduate at a nearby college and his housemates all work. Besides being a student, Henry is a photographer and has a darkroom in the basement.

DISABILITY

Three years ago Henry was in an accident that resulted in an incomplete injury at the C7 level so that he is a quadraplegic with balance. He has the use of the large muscles in his arms and shoulders with limited ability to flex his fingers. He has no grip or fine muscle coordination in his hands. It is difficult for him to turn to reach things behind him at shoulder level and he leans forward to pick things up off the floor only when holding on to the back of his chair with the crook of his elbow or wrist.

WHEELCHAIR DIMENSIONS

Henry’s chair is a narrow adult model without arms. It has a minimum turning circle diameter of 54”. Henry uses a 2” cushion.
DAILY ROUTINE

6:45 Henry wakes up and sits up by hooking his arm over the trapeze bar hung above the bed. He then transfers to his w/c and pushes into the bathroom and transfers to the toilet. When he is done, he transfers to his w/c and backs out of the bathroom and turns around so that he can back into the bathroom in a position suitable for making the transfer to the tubchair.

7:30 He takes a shower, cleans his urinal and dries as much as possible before transferring back to the w/c. He combs his hair at the sink and pushes to the closet to pick out his clothes for the day and puts them on the bed.

8am Henry then transfers to the bed, dries himself where he could not reach before and puts on his clothes. After dressing, he rests for a few minutes then transfers back to his chair.

8:30 He then pushes into the kitchen to make breakfast. The simplicity of breakfast is directly proportional to
the amount of time he has to prepare it.

8:45 Henry rinses the dishes, gathers up his books and papers, does a bit of last minute straightening and gets his jacket.

9am He pushes out of the house, rolls down the back ramp and uses the van lift to get into his van, anchors his chair in the driver's place and drives to school.

4pm Henry is usually home in mid or late afternoon. If his girlfriend comes over, she does most of the cooking while Henry washes the rest of the dishes or chops a few vegetables. As housemates and their friends arrive, the kitchen gets quite crowded since everyone is responsible for their own food and often two separate meals are prepared at once. On quieter evenings, when Henry makes his own dinner, he usually makes a "one-pot-meal" using a lap board to carry things from refrigerator to sink to stove.

6pm Henry usually eats with his plate on the lapboard while his housemates gather in the livingroom and sit on the couch rather than sitting in the diningroom together.

6:30 After dinner Henry does the dishes and may hang around the livingroom talking to his housemates, or he may have to study or work in the darkroom.
CHOOSING THIS HOUSE

Henry does not see this house as a permanent residence, rather as a stepping stone on his way to settling somewhere. This house was chosen because it was close to his parents, it was a reasonable cost to purchase and to adapt, plus his friend also liked it. He also liked the fact that the driveway went all the way around the house and that there was room for the ramp. It was very important to him to have a private toilet. If this were to be his permanent home, he would modify the tub and build a ramp from the bedroom exit.
HOUSE EVALUATION 3

ADAPTATIONS

On moving day the ramp (a) to the back door was constructed in about five hours. The only other items necessary to make the house basically accessible was to add an extension to the back door handle (making it a lever rather than a knob) and to remove the door to the master bathroom(b).

Within the first week handles(c) were added to the upper cabinets in the kitchen and the trapeze(d) was installed over the bed. With
these changes plus the tub chair and the toilet seat Henry could be completely independent(e).

In the next two years the dark-room was installed in the basement(f), the elevator (g) was constructed and the porch(h) was raised 6" to be level with the diningroom floor. When one roommate installed a wood stove in his basement room, the chimney was positioned so that it would add heat to Henry's bedroom.

UNADAPTED ITEMS

Since Henry can manage very well in the kitchen by approaching the appliances from the side and because all of his roommates also use the kitchen there are no plans to lower the counters or to create knee spaces.

The hall is a reasonable width (36") although if the doors were wider, the turns into the bedrooms would be much easier.
The door to Henry's bathroom is so narrow that he has to pull through using the door jambs yet he has not widened it due to the cost.

Since the driveway loops around the back of the house, there is no need to build a ramp to the front entry. Besides this functional reason, Henry does not want to advertise the fact that he is chair-bound to all passersby. If the door from the master bedroom were ramped, it would serve as an emergency exit in case of fire. Henry has chosen to take the risk rather than to bear the expense.

The author discovered that Henry spends a lot of his time leaning on nearby counters and furniture. It may be that he is compensating for the lack of arms on his chair.

The built-in oven is at a height that is quite useful (36" to the bottom) and the nearby pantry has sufficient storage space at the appropriate height for his use.
SUMMARY

Henry's attitude has been to adapt only if there is a necessity born of functional or access requirements. Those items adapted for access are: the ramp, the elevator, the door handle extension, removing the bathroom door, raising the porch and adding handles to the kitchen cabinets. Adaptations for functional reasons include the toilet seat, the tub chair and the darkroom.

There are no renovations planned for the near future. If Henry were planning to stay here longer he would probably widen the bathroom door and build a roll-in shower.

He might also build a ramp from the master bedroom door to provide an emergency exit.

If he were to adapt the bathroom with a roll-in shower and a wider door with a sink he could roll under, he could probably cut his morning routine down by more than half an hour, making it much easier for him to get where he is going.
Family 4

FAMILY STRUCTURE

The Burnham household is composed of Russell (Russ), 57; Wenonah (Nonie), 60; and their youngest son who is temporarily back at home. Nonie manages the house and Russ works for G E. They have raised five children in this house.

DISABILITY

Nonie contracted polio when she was 35 and her youngest child was four months old. The effects of polio are different from spinal cord injuries in that there is motor paralysis without loss of sensation. The polio virus attacks the anterior horn cells of the spinal cord (see fig. ). If 50% or more of the cells are lost, the muscles ennervated from that area show weakness. Polio may affect only one side of the cord and may skip segments so that there is no predictable pattern of motor function as there is with spinal cord injury.

Nonie has the use of her right leg, and left arm and hand although she has very little lifting strength in her arm. She has no problem with trunk balance and can lean over to reach things from low cabinets. She does not turn around to reach things behind her at shoulder height.

WHEELCHAIR DIMENSIONS

Since Nonie pushes her chair with her foot, she has no need of handrims and uses only one footrest. The lack of handrims makes the chair 2" narrower. She has desk arms on her chair so that she can approach tables comfortably.
DAILY ROUTINE

6:10 The alarm wakes Russ.
6:20 He gets out of bed and walks downstairs to the kitchen and puts water on to boil.
6:25 He walks to the downstairs bathroom to brush his teeth, use the toilet and shave.
6:30 After washing, he walks back to the kitchen to boil an egg, make toast and pour coffee and juice. He eats and reads the paper at the dining table.
7am He clears the table, does the dishes and walks upstairs to dress and take the paper to Nonie who has just awakened.
7:10 Russ walks back downstairs and out the breezeway to the car to go to work.
7:15 Nonie uses her hoist to transfer to her wheelchair and pushes into the bathroom to wash her face and brush her teeth. She uses the bathroom hoist to transfer to the toilet and back to her wheelchair.
7:30 She pushes back to the bedroom/studio to dress and read the paper. Her morning activities vary from housework and paying bills to shopping to studying for one of the two courses she is taking at the local community college. When she goes shopping, she uses the hoist in the workroom to transfer to her electric wheelchair which is transferred to her van with a lift.

One of her more recent projects has been to get more parking for the handicapped at a nearby shopping center. As a result she has had to
Again using her hoist, Nonie transfers from the bed to her wheelchair. She usually does coursework or reads in the afternoon if she does not have phone calls to make. At one time she ran a small business selling items she made on her knitting machine. Now it is more or less a hobby or filling a special request for her argyle socks.

Regardless of the menu, Nonie begins to prepare dinner in the mid-afternoon. She has developed a series of menus and recipes that are...
quick and easy for her to prepare. If she wants fresh peeled potatoes or some other item that takes two hands to fix, she schedules that item for a time when there is someone around to help. It is not worth the time it would take her to do it herself.

5pm Russ comes home from work and Nonie serves dinner at the dining table.
5:45 Russ clears the table, does the dishes and makes coffee.
6:15 After coffee, Russ does the chores that need to be done and may go to his workshop to work on his latest project. Nonie takes the elevator back upstairs to finish her reading or her studies. Later they may watch TV before going to sleep. Several nights per week they go to the local community college for class or they may go to the grocery store.
ADAPTATIONS

The Burnhams built the original house themselves and moved in in 1946. They liked a house without a basement and thought 1½ stories would save energy. Nonie contracted polio in 1955 and when she came home from the hospital the front room (2) was added. This room included a toilet and a hoist that allowed her to transfer to the bed or the toilet. The garage and breezeway had been added in 1952 (3). In 1962 the 20'x30' shop and bedroom/studio addition was made (4). This included an elevator that Russ bought for scrap and reconstructed. With this addition, the sink in the downstairs bathroom was converted for use as a kitchen sink and Nonie's lower kitchen work shelf was
In 1965 they added a porch off the workshop where Nonie hangs clothes in good weather.

A couple of years ago they added the hoist in the workshop so that Nonie could make the transfer there to her electric chair that she uses for shopping. Within the last year the downstairs bath was converted to a roll-in shower so that Nonie's weekly shower is much easier for them.

added. When Nonie and Russ moved upstairs, a hoist was added to the bathroom and the front room was converted to a den (hoist and toilet removed).

UNADAPTED ITEMS

The front door has never been ramped because Nonie's front room was ramped and because the front door is very seldom used. A separate kitchen workspace was added rather than adapting the existing kitchen. This seems to be because it was easier and because the rest of the family uses the regular kitchen. Another factor may be that Nonie had someone come in to help her with the children and the house until all the children were in school.

The mail is delivered to the table inside the breezeway door so that Nonie does not have to go out to the street.

The hallway on the second floor of the original house is only 27" wide and could not be widened without making structural changes at a greater expense than they were willing to make.
DISCOVERIES

In the original house they made the wall switches high enough to be out of the reach of small children - now they are too high. They also discovered that desk arms on the wheelchair make it much easier for Nonie to pull up under the table.

Many items at standard height are useable, but the stove and sink must be lower for Nonie. Wall-hung fixtures work well for rolling the chair under and for making room for the foot rests of the wheelchair.

SUMMARY

Nonie spends most of her time in her bedroom/studio. Russ spends most of his time in the workshop. They spend most of their time together in the dining area. Their attitude toward their house is that function comes first. They are "do-it-yourselfers" and Russ is always working on something to make things work easier - from the headset on the phone to a privacy screen for their car so that a portapotty can be used on road trips (since there are so few accessible public toilets).
Family 5

FAMILY STRUCTURE
Don and Kris Sherman are in their early thirties and moved into this house shortly after they were married five years ago. Don is active in the Paralyzed Veterans of America and serves as the local chapter president. Kris is an occupational therapist at the VA hospital.

DISABILITY
Don was 19 and in service when he was injured. He is a T12 paraplegic with normal use of his body above his waist. He has good trunk balance and is not limited in his ability to reach things from his chair.

Don's wheelchair is a junior adult model (2" narrower than the standard adult model) and is without arms. He usually uses a 1" cushion.
DAILY ROUTINE

6am Kris wakes up automatically, gets out of bed and walks to the bathroom. After using the toilet, she lets the dog out of the house and goes back to the bathroom to wash. She then goes back to the bedroom to dress and then returns to the bathroom to put in her contact lenses and to brush her teeth.

6:30 She lets the dog back in the house, straightens up the living room, washes any dishes and finishes any necessary chores.

7am Kris gets her coat from the closet and leaves for work.

9am Don is awakened by the clock radio. He transfers to his wheelchair and wheels into the bathroom to wash. He then transfers to the bed to put on socks, shoes and trousers. He transfers back to his wheelchair and wheels into the half bath across the hall from the bedroom.

9:15 He transfers back to his wheelchair and wheels into the bedroom to pick his suit out of the closet. He then transfers to the bed to put on socks, shoes and trousers. He transfers back to his wheelchair and wheels into the tub to take a shower.

9:30 There Don shaves and brushes his teeth. He then wheels back to the bedroom to dry his hair and put on shirt, tie and vest.

9:45 He then wheels to the kitchen for juice and vitamins; wheels to his office to pick up papers and briefcase and then wheels to the bedroom to get his jacket.

10am He wheels out the kitchen door, locking it behind him and goes out the porch and down the ramp to the driveway. He uses the van lift to get into the van and drives off to his meeting.
+5pm Don's schedule varies, but usually he is home in the late afternoon.
+7pm Kris comes home and starts dinner. The newly remodeled kitchen has much more counter space than before. Don may help chop vegetables on his lap board. When Don cooks, he approaches the stove and the sink from the side. This suits him very well and there was no plan to provide knee space when the remodeling was planned.

7:30 They sit down to eat at the dining table. After dinner they put the dishes into the dishwasher. There is no set pattern for their evenings.

CHOOSING THIS HOUSE

They wanted to live in the suburbs so that they could have some land and some privacy.

This particular house was the right place and the right price. The halls were wide enough and the baths were reasonable so they bought it with the knowledge that they would remodel it as much as needed to suit their lifestyle. Therefore a major factor was the quality of construction—it had to be worth remodeling. Since Kris liked it so well they bought it without any other considerations for accessibility.
HOUSE EVALUATION 5

ADAPTATIONS

The only addition necessary for moving in was the construction of a temporary ramp to the front door. Later on a "stair-cat" was added so that Don could get to the basement to exercise. He usually uses it only in bad weather.

Two years ago they did a major renovation job to take care of all the needed adaptations at...
once: all the doors were widened to 36", the permanent ramp was added to the side porch and the walk and driveway for the van were added in front. The ramp was put on the side of the house so that it would fit in better with the house and so it would have a gentler slope.

When they remodeled the kitchen they built shelves and a phone desk for Don.

UNADAPTED ITEMS

When the kitchen was remodeled, there was no thought to make it wheelchair accessible with knee spaces and lowered cabinets. This is due in part to the fact that Kris is the most frequent cook and that when Don cooks he can manage with everything at standard heights. They did make sure that the bunwarmer was at an appropriate height and there is a pull-out cutting
board that will serve his needs.

The bathroom was not adapted because Don has no trouble transferring to the tub and feels no need for a roll-in shower. They did not make an emergency exit from the bedroom since it is virtually on the second floor over the garage.

SUMMARY

Don's first house (now occupied by his former wife and children) was constructed to the VA's standards under their grant and loan program. His experience with that house served to guide the decisions he made about how to adapt this house - especially widening the doors. His attitude is that he needs to keep in shape so that as long as he can adapt his behavior, there is no need to adapt his house.

There are no future adaptations planned though Don would like to have a more accessible garage or a covered path from his van to the house.
Family 6

FAMILY STRUCTURE

The Young household consists of David, 24, and several roommates. David currently works at the Boston Center for Independent Living and will be a graduate student in the fall. All of his housemates have jobs. David has rented his first floor apartment for the past three years. It is financed via a Section 8 housing subsidy. His roommates get a reduced rent from David in return for assisting him on a daily basis. They are friends and roommates first, assistants second, so that the family structure here is very similar to family 3: a group of single people living together cooperatively.

DISABILITY

David was injured when he was 19 and is functionally a C4 quadriplegic. His injury is neurologically incomplete to the extent that his condition is called "upside-down quad". He has virtually no use of his hands and arms yet has enough strength in his hips and legs to turn himself over in bed at night. This is useful in preventing bedsores from developing from staying in one position for too long. David has partial trunk balance and controls his physical environment with a mouthstick.

WHEELCHAIR DIMENSIONS

David's chair is battery powered and is narrower and longer than the standard manual chair. He guides it with a chin control and has his mouthstick, cup, and door buzzer mounted on the lapboard.
DAILY ROUTINE

6:50am A roommate comes into David's room to make sure that he is awake, bringing a pitcher of water and a washcloth.

6:55 After his face is washed and he has had a large drink of water and taken his medicines, he and his roommate work through his range of motion exercises. Then the roommate empties and cleans the urinal and helps David get dressed for the day.

7:25 A second roommate is awakened in order to give David a lift into his chair which is brought in from the kitchen where it was recharged overnight. David settles into his chair and one of the roommates often goes back to sleep.

7:35 David then checks around his room to remind himself of all the things he must do during the day and all of the things he has to take with him. He hits the light switch with his stick and drives down the hall to the kitchen for breakfast.

7:40 Breakfast varies from an instant breakfast served in his cup to an omelet - depending on who is making breakfast and assisting and how much time there is to spare. If breakfast is to be a big production, he either gets up earlier or must leave later.

7:45 David is ready to leave for work. His roommate gathers up all the things to be taken along and dons his cape and hat if it's cool. David hits the door switch to open the
inner door and the roommate must open and close the outer door. In cold weather this is an awkward operation since the hall is narrow and short. With a bit of assistance, David backs down the ramp and into the van and is driven to work.

+6pm Coming home David can negotiate the ramp himself (moving forward) and if the outer door is open, all he has to do is open the inner door with his remote control. Dinners are erratic in schedule depending upon who is cooking and whether they have decided to send out for dinner. It is rare that all the roommates are together at the same time for dinner.

If dinner is being cooked, David hangs around in the kitchen giving moral support and conversation to the cook(s). When dinner is served, David pulls up to the kitchen table so that the person assisting is sitting across the corner from him. All available roommates help with the cleanup after dinner.

+7pm After Dr Who is over there is no set pattern for the evening but often friends or the upstairs neighbors will stop by for a beer or to listen to the stereo and chat. Any of David's friends will take responsibility for filling his cup. Other evenings all of the members of the household work on their separate projects. In the living room, the controls for the stereo...
and TV are easy for David to operate with his mouthstick. Pressure switches or toggle switches work best. In his room, things are set up on shelves and stands around the perimeter so that everything is within mouthstick reach. His reading is on an easel shelf, his typewriter, phone, water pitcher and calendar are all at the proper height for convenient use (±26" to 40" from the floor).

When David is ready for bed, he lets his roommates know and they give him a lift into bed, help him out of his clothes and to get comfortable for the night. Though this process takes only a few minutes, it may turn into a long household conversation with all the roommates sitting around on his bed. Here the livingroom and kitchen are the social centers of the house. Though the two rooms are separate, people move easily from one to the other. With the existing furniture, doors and the window seat, it is hard to arrange the livingroom to
accommodate over five people comfortably.

CHOOSING THIS HOUSE

Before moving into this apartment David lived in an MHFA housing project in Jamaica Plain. His major reason for moving was the desire to live with more people in a larger place. He applied for and received a Section 8 subsidy and he and his girlfriend went to a number of real estate agencies to look for a suitable place. They were able to narrow their search to a few listings of first floor apartments with few steps at the entry. David rented the apartment sight unseen because his friend understood his needs for generous circulation space and recommended this apartment. David has not had the bathroom adapted because he and his roommates have been able to adapt their routines instead.
HOUSE EVALUATION 6

ADAPTATIONS

The only adaptation made before David could move in was the ramp (a) to the back porch. Since moving in, the light switches (b) have been changed so that he can operate them with his mouth stick. He has also added a remotely controlled door switch (c) with three control points: inside the kitchen door, in the entry hall and on his lap board.
David's room has been arranged as a functional bedroom/study with furniture gathered from various yard sales. The major criterion for choosing these pieces is that they be the right height. Second they should look homey and aesthetically pleasing without losing their functional value. His bed has been put on blocks so that the transfer from bed to wheelchair is easier. His closet door has been removed so that shelves can be put in front of it and still allow for use of the closet.

UNADAPTED ITEMS

Since David cannot lift things, there is no need to adapt the kitchen with appliances that can be operated with his mouthstick. To build a ramp to the front entry would be a mistake since there is such a steep grade and so little area in which to build a ramp of a reasonable slope.

A wider bathroom door and a roll-in shower would make his weekly bath much easier for all concerned, but David has not yet gotten around to having this change made. David and his roommates are able to manage well enough that this expensive renovation can wait.

DISCOVERIES

David's most pleasant discovery is that his "L"-shaped room is much more functional than his
previous rectangular rooms. This is because it allows him much more wall space for arranging the things he needs to have within reach. He would like to have a similar arrangement in his livingroom.

He has also found that old houses seem to have far more generous circulation spaces than newer construction. He can turn $360^\circ$ in the hallway outside the kitchen and livingroom, yet the end of the hall near the front door is quite cramped when there is a wheelchair plus several people trying to put on coats and say goodbye.

### SUMMARY

There have been as few adaptations made as possible. This is due in part to the fact that this is not a permanent residence for David and in part due to his attitude that things should be made as functional as possible as simply as possible. If he were to make any adaptations in the future, creating a roll-in shower would be the only one. The only changes planned at present relate to making the living room a more social place. Since the wheelchair takes up so much room, it is hard to arrange the furniture so that David can sit close enough to people to carry on a private conversation at a social gathering.
FAMILY STRUCTURE

The Collette family is composed of Tom, 44, and his eight children who range in age from 21 to 10 years old. His wife passed away less than a year ago. One daughter is away at college, the rest of the children go to local schools. Tom is active in a number of sports and in the Boy Scouts and the Paralyzed Veterans of America (PVA).

DISABILITY

Tom was 19 years old and in the service when he was injured. His injury is at the L1 level so that he has normal functions from the waist up. He can stand with braces and walk with crutches when necessary. He has no problem with trunk balance or with reaching things from his chair.

The wheelchair is a regular adult model with regular arm rests. He usually uses a 2½" cushion and carries, keys, glasses and other items in a pocket just inside the armrest.
DAILY ROUTINE

+7am A couple of the boys come back from their paper routes and the rest of the children wake up. They make their own breakfasts and get ready to go to school.

7:50 The last daughter out of the house wakes Tom as she leaves for school. He dozes for a few minutes.

8am Tom rolls to one side of the bed and pulls up the window shade and rolls to the other side for the other shade. The bed is at a 45° angle to the wall so that both shades are within reach. Next he puts on his socks which were left next to the bed the night before. He transfers to his wheelchair, picks up his pants and sweater and pushes into the bathroom. As he passes the childrens' rooms, he checks to make sure they have made their beds.

8:15 He pushes into the bathroom puts his clothes on top of the hamper and transfers to the toilet. When he is done he transfers back to his wheelchair and puts on his sweater and pants.

8:25 Next he pushes to the sink, takes a small hand mirror out of the nearby closet and combs his hair after washing up. He then pushes down the hall to the kitchen. He makes coffee by turning "sidesaddle" to the sink to fill the coffee pot then turning around to approach the stove from the side as well.
8:30 Tom then starts the dishwasher if necessary and sets out cup and saucer. When the coffee is made he picks up the cup in one hand and with the other pushes over to the dining table to drink the coffee and read the paper.

8:50 He pushes to the sink with his dishes and then goes to the bedroom. He slips off his trousers and transfers to the bed. He then picks up his braces, disengages the shoes and puts them on. After putting on the braces he transfers back to his wheelchairs and puts his trousers back on.

9:15 Next he pushes to the bathroom to shave and brush his teeth. He puts all of his gear back in the closet and transfers to the toilet to empty his bladder once more before going out.

9:35 Tom then pushes to the kitchen, gets his coat out of the closet, leaves a note for his children with any messages or instructions for the day and then pushes through the breezeway to the garage. He opens the garage door with the remote control, transfers to the car and is off for the day.

He carries a second wheelchair and a pair of crutches in the car at all times.

+4pm One of the older girls will start dinner. Tom's schedule is irregular, but he is usually home by this time to give advice on the cooking and to help make salad with the rest of the family. The youngest children set the table so that all of the children have a job to do and participate in dinner. The crossboard at the dining table is too low for Tom to get his knees under so that he must fold the footrests of the wheelchair away and put his feet on the floor.

5pm The whole family gathers for dinner. During dinner they discuss any problems that have come up during the day or plan the next camping
trip. They also plan dinner for the following night.

6pm Everyone clears their own dishes to the sink. One of the children goes downstairs to get the next night's dinner out of the freezer and another child is in charge of the dishes. Tom and the youngest children go over homework at the dining table. Afterwards everyone dispurses to do chores such as laundry and other homework. Later in the evening there may be friends over to visit plus the usual range of teenagers' activity from TV to music to working on the car to playing pool. Tom often watches TV or works on the PVA newsletter til time to go to bed.

The kitchen is the center of family activity in this household. Most of the family takes part in food preparation, they all eat together and this is the site of family conversations and planning sessions. The livingroom and the recreation room downstairs are secondary and serve mainly for TV, having friends over and listening to music.
CHOOSING THIS HOUSE

This house was specially designed to meet Tom's needs through the Veterans' Administration's 702 program. This program makes both grants and low interest loans available to disabled veterans for the purpose of building or adapting their homes. Tom's home was built within a year after his injury. He had talked to other PVA members and chose an architect who was also confined to a wheelchair. He knew that he wanted a ranch-style house and knew generally what to expect because he had visited other adapted homes and knew the VA's requirements. He left most of the details to the architect. At one point he did visit the construction site to discover that the island/bar in the kitchen made the kitchen much too small as it was laid out. He decided the leave out the island and to use the space for a dining table in tead.

He chose the neighborhood because it was close to relatives, convenient to other places (near two major highways) and because it was not too far away from the VA hospital.
HOUSE EVALUATION 7

ADAPTATIONS

This house is the only one in the study specifically designed to accommodate a chairbound owner. Most of the changes and additions that have been made have been for the purpose of expanding the living space for a growing family. The basement was finished, the breezeway enclosed, two bedrooms were added, the pool was added along with the patio and screened in house. The only
adaptation that had to be made was to build a ramp over the five steps from the breezeway to the back yard. This change was made just five years ago after Tom finally got tired of going around the house to get to the back.

He also added heating wires to the roof to melt the snow and ice out of the gutters and drain pipes in the winter.

The halls are 48" wide, the doors are 36" wide and the bathroom is adapted according to the standard. Currently the roll-in shower is used for the sewing machine since Tom would just as soon transfer from his wheelchair to a straightbacked chair and from there transfer into the tub.

UNADAPTED ITEMS

The kitchen was never designed to the specifications of a chairbound user. Over the years Tom has developed his habits so that when it came time to put in a dishwasher and replace the cabinet doors (deep chair scuffs), there was no thought of providing knee space or of lowering the cabinets for one member of the family. Now his children take responsibility for the cooking and there is no need to make special provisions for Tom.

Tom's wife chose most of the furniture with the major criterion being that she preferred the colonial style.

SUMMARY

Tom's house works very well for him and helps to make the case that designing for wheelchair access is much more efficient than making renovations.

The only changes that Tom would make are for convenience. He would like an elevator to take him down the stairs to the basement in bad weather, but
there is not enough room at the bottom stair landing.

The other change he might make as the children move away is to move the washer and dryer upstairs.
CASE STUDY SUMMARY

The matrix below lists some of the characteristics of the chair-bound person(s) in each of the case families and shows the type of adaptations that were made in each home.

None of the families widened hall dimensions or adapted windows for easier opening or put in grabbars. Although, in family 2's bathroom remodeling, grab bars came with the prefabricated shower. Many added door or cabinet hardware to make the handles easier to operate. All families added a ramp to their entries - even the home designed to accommodate a chair-bound owner had to have a ramp added in the back. Most families chose furniture for the appropriate height and ease of use although often style and aesthetic considerations were overriding factors. Controls for appliances are critical for quadraplegics who lack fine muscle coordination and cannot grip or pinch controls. Toggle switches, push buttons and rocker switches work much better than control knobs that must be grasped and turned.

Where hoists and trapezes were added, either the ceiling structure was planned for the extra load or the existing structure was judged to be strong enough to carry the extra weight. In newer construction, the structure might not be strong enough to bear the weight of a hoist plus a heavy person due to the need to economize.

All of the kitchens in the case study homes are large enough to accommodate 180° turns and most accommodate a 360° turn. In family 4's kitchen, where there is no turning room, an extra work space was added at the proper height with plenty of surrounding room.
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### Characteristics
- **Paraplegic**
- **Quadriplegic**
- **Post-Polio**
- **Female**
- **Male**

### House Adaptations
- **Front Ramp**
- **Side Ramp**
- **Garage Ramp**
- **Back Ramp**
- **Widen Doorways**
- **Specially Designed Furniture**
- **Roll-In Shower**
- **Raised Toilet Seat**
- **Tub Seat/Shower Seat**
- **Add Bathroom Mirror**
- **Kitchen Knee Space**
- **Lowered Kitchen Counter**
- **Special Purchase Kitchen Equipment**
- **Second Level Access**
- **Hoist/Trapeze**

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Figure 4, Case Study Summary
Although there was little evidence of a tendency for the case study families to buy less furniture, there was a noticeable tendency to place furniture against the wall and leave the middle of the room open for traffic. This is in keeping with national tendencies. Howell documented a similar phenomenon in apartments for the elderly.

For this author, the most striking quality about the case studies is the need to organize both space and time in order to compensate for the lack of ambulation.

Factors for choosing a house vary from family to family but the priorities seem to be similar. Basic accessibility is the most important factor beyond locational factors. The next most important set of priorities deals with family norms and preferences and the fit with the available housing and economic resources.

Themes
The common denominator for basic accessibility in all the case families has three aspects: 1. The most frequently used entry must have a ramp that the chair-bound family member can negotiate. 2. The interior circulation must be of adequate dimensions. 3. The bathroom must be adaptable.

The steepness of the ramp is more often closer to the performance level of the user than to the 1 in 12 slope recommended by the standards and guidelines. A shorter, steeper ramp than the standard slope is preferred because it costs less to construct and is generally considered to look better.

Interior circulation is considered to be adequate if the most used and major spaces are easily accessible via wheelchair and the least used spaces are accessible with only slight or moderate difficulty or inconvenience.
Only inaccessible storage spaces are acceptable since alternatives are usually available.

Standard bathroom doors are narrower than doors to other rooms. If the fixtures can be made accessible, and a degree of privacy maintained even with the door removed, an inconveniently narrow bathroom door will not be the basis for not moving in to a particular house.

The mode of adapting the fixtures depends upon the degree of motor control, the preferences and the perceptions of cost/benefit of the owner.
SAFETY

There are three major areas of safety concern in a household where one of the members has a spinal cord injury that are not present as acutely in households of able-bodied members. 1. An emergency exit is desirable from the master bedroom or from the bedroom of the chair-bound member. Given the mobility impairments, there are few, if any, alternative exits as there are for the able-bodied. Although only two of the case study families have this feature in their homes, all acknowledged the issue and have made accommodations ranging from never being left alone while in bed to rationalizing the risk as being far less than the expense.

2. It is a well-known fact that the bathroom is the site of more household accidents than any other room in the house. For a person with mobility impairments, safety is a far more critical issue due to the likelihood of limited or poor balance and the nature of the transfer operation from wheelchair to fixture. For this reason space is necessary for the proper approach to tub or toilet or shower or sink. The controls also have to be within reach so that one's balance is not lost in reaching to turn on the water. While one of the families studied installed grab bars, all have made the necessary accommodations to support the chair-bound family member either through renovations and equipment or through changes in the family routine. Only in family four is reach from the tub seat to the controls at the maximum performance level of the disabled member. "It's a scary reach."

3. Safety in the kitchen consists mainly of protecting the chair-bound individual from burns. Since there is loss of sensation and reflexes with spinal cord injury, all hot water pipes that might be accidentally bumped must be insulated. Appliance controls must be operable without the need to grip and must be positioned away from hot elements. The height of the oven and range top should be within reach of a seated person so that the potential for spills is
reduced. At the standard counter height of 36" it is virtually impossible for a seated person to see whether the water is boiling without lifting the pot off the stove. One family in this study has a friend who was badly scalded when a pot of boiling water she was checking slipped into her lap.
EFFICIENCY

One of the most striking features about the daily routines in the case studies is the amount of time and/or the number of transfers it takes to get started for the day. This situation is very similar to that documented by Berk and Berk: "Apparently, one response is to get up somewhat earlier to get a headstart on a variety of household chores... both employed and unemployed wives may have little discretion in how the early morning hours are sequentially organized. One important consequence is that the day to day experience of the early morning hours may be characterized by high levels of tension and anxiety."1

Add to the usual tensions and chores the need to clean urinals and catheters, to make numerous transfers and one can immediately see the contribution that an adapted bathroom can make to the quality of life for the chair-bound person.

In order to speed up the morning routine, the route from the bed to the bathroom should be as short and direct as possible. Turning and approach space should be adequate for smooth turns and easy transfers. Often, roll-in showers save transfer time, especially for people with high level injuries, without any interference in the use by ambulatory members of the family. Knee-space under sinks, mirrors and storage at the right height can greatly increase the efficiency of the morning routine as well.

The alternatives to adapting the bathroom to an individual's particular needs are to increase the amount of assistance given by family members or aides, to get up earlier and take the extra time or to change as many tasks as possible to simpler or less frequent schedules. The choice of a combination of these alternatives could be the difference between being able to get to work on time and not being able to hold a job.

Household chores are often under the same constraints as the morning routine, as are meal preparation and entertaining. The trade-offs are always between the costs of making physical adaptations, relying on ambulatory family members to give assistance, simplifying the task, paying to have someone outside the family to the work or eliminating the task or shifting it to a less frequent schedule. So beyond designing for very basic accessibility, the most important goal is to design for efficiency and ease of operation of the household from a wheelchair.
The following charts from Berk and Berk's book LABOR AND LEISURE IN THE HOME is included for the purpose of comparison with the case study diaries. The content of the early morning hours are strikingly similar.

Figure 3.1: Production Genealogy for Families in which the Wife is Unemployed (5:00 A.M. to 8:59 A.M.)

Figure 3.3: Production Genealogy for Families in which the Wife is Employed Full-Time (5:00 A.M. to 8:59 A.M.)
Rehabilitation available to people with spinal cord injuries varies from a small general hospital's attitude of "heal the sick and injured" to a rigorous training program that prepares its clients to overcome as many obstacles as possible in order to live independently. Anecdotes abound about people who have lived in nursing homes so long that they are afraid to try to live in a family situation as well as about people who do things the hard way because it is more "normal". Neither of these extreme positions is advocated by this author.

Often rehabilitation programs provide their clients with a philosophy for dealing with their disability which includes attitudes toward their disability, expectations about their maximum level of performance and information about renovations, devices, equipment and strategies that will enhance their performance.

Within this framework of attitudes, expectations and information, families make their decisions about adapting their homes, their use of social services, hiring aides and the use of other available supports. The rehabilitation program is the first and often primary source of information about the choices that are available and appropriate in regard to architectural changes that might be made to one's home.
ROLES/FAMILY SUPPORTS

From the case studies it is evident that having a carpenter or fix-it type person in the family is a great asset whether the outcome is a specially designed changing table for the infant's diapers or a chain latch closer for the screen door. Family support also takes the form of accepting additional chores or offering physical assistance for difficult operations.

Berk and Berk, in their study of household tasks, found that for a sample of over 800 wives and 500 husbands the household tasks fall mainly on the shoulders of the wives - whether they have full-time jobs or not or whether there are children in the family or not. This pattern is reflected in the case studies presented here and is emphasized by the pattern of 110 kitchen adaptations. Whether the kitchen is adapted or not depends upon the role played by the disabled member of the family. If the caretaker (usually the wife) is disabled, the kitchen is much more likely to be adapted to support the maintenance of that role. Only in family four was there a substantial shift of the household chores to the man of the house, but not to so great an extent as to suggest role-reversal.

There is little evidence from the case studies to suggest that having a disabled family member will increase pressure for role-reversal. Rather it seems that the division of labor will be shifted slightly and that adaptations to the house will be made to support and reinforce the chosen roles instead.

In households where there are both disabled and able-bodied adults, it seems that the pattern is to adapt areas such as the bathroom (where use by both is served by the adaptation) and either to not adapt or to add to the kitchen (where requirements are in conflict). Generally the storage that is within reach from the wheelchair is reserved for the chair-bound person, while the upper shelves are used by the family members without reach limitations.

ECONOMIC RESOURCES/SOCIAL SERVICES

Having a spinal cord injury is a very expensive proposition. Beyond medical expenses there are needs for adapted transportation (lifts and/or hand controls), an adapted home (a minimum of an entry ramp and suitable bathroom) and some special equipment. Living with one's family is by far less expensive than living in a nursing home or other institutional setting. An adapted home is one factor that can mean the difference between independent living and being institutionalized.

There are a number of agencies that either have funds or information about funding and services available to support adaptations for all types of disabilities: the Department of Housing and Urban Development (HUD), Vocational Rehabilitation (VR), the Veterans' Administration (VA) and the Social Security Disability Insurance program (SSDI). There are different eligibility requirements for each of these programs.

There is also a growing number of local advocacy groups that make it their business to provide information. In Boston, the Boston Center for Independent Living (BCIL) and Adaptive Environments serve as counseling and advisory groups for the general public.

There is always a question of where to go for funds if one is not independently wealthy. Each state administers the Federal programs within its own set of guidelines and standards; each large city has its own set of advocacy groups. The amount of money available as well as the way these programs and services are administered vary over time as well as geographically. Rehabilitation programs are usually a primary source of information about what is locally available.

One's income level relates to the need for outside funds and one's dependence upon available social services. Adapted housing can contribute to one's ability to hold a job and can therefore reduce the need for external funding.
RAISING CHILDREN

One of the initial questions that generated this study was: What, if any, are the intrinsic differences between raising children in a household where the parents are able-bodied as opposed to a household where one or more of the parents are wheelchair bound? The answer seems to be that the time it takes to get things done is the major spatial-temporal difference. This study cannot cover the potential psychological differences.

Observation and interviews suggest that parenting from a wheelchair is essentially similar to parenting on two feet. Children learn to include a wheelchair in their world just as they learn to include any other useful piece of equipment. A neighbor of one of the study participants reported that his young son asked if he might have a wheelchair because it looked like so much fun.

Strategies for parenting are very much like those for coping with the activities for daily living. Equipment must be chosen carefully: a crib that allows an infant to scoot out or reach or requires one to lean so far over as to lose one's balance is unacceptable. On the other hand, a harnessed toddler can easily be kept in reach. Behavior can be modified to meet a particular situation: a quadriplegic father learns to change diapers with his teeth and hands instead of his fingers; a small child learns quickly to climb onto his/her parent's lap and hold on for a safe ride. Part-time assistance may be hired to supplement parental care. Adaptations may be made to the physical environment to give added support: fenced yards are very important until the children learn to come when called.
While issues of basic access, safety and efficiency are far more critical to supporting the activities of daily living, the question of ramps and the images they project became an interesting part of this study. An obvious ramp to the front entry of a home advertises to the neighbors and to all passers-by that someone in that house has a disability. Such an advertisement is in direct opposition to the concept of normalization - that the home environment should not include any aspect that gives the appearance of an institution. Another aspect of the image of a ramp is that many people attribute other disabilities (either mental or moral) to one who has a physical disability. This set of ideas is clearly elaborated by Goffman in his book called STIGMA.

To be psychologically enabling, one's home should be as unstigmatizing as possible. It should be as "normal" as possible and within the housing norms of the culture to which the resident belongs. It is not surprising, then, that only one of the seven case study families had a ramp leading to the more formal front entry. Even that ramp was not obvious from the street. "The house therefore nicely reflects how man sees himself, with both an intimate interior, or self as viewed from within and revealed only to intimates who are invited inside, and a public exterior (the persona or mask, in Jungian terms) or the self that we choose to display to others."1

The ramp is a symbol of vulnerability and physical frailty and is most often relegated to the private side, the rear entry, the less formal part of the house (see p ). This should be a strong hint to designers that ramps should blend in with the landscaping so as not to stand out as a stigmatizing symbol. The sketch below is taken from "Wheelchair House Designs" by the Eastern PVA in New York. One participant in this study described it as the 'perfect' rampdesign - useful, yet totally unobstrusive and as if the ramp were the only feasible way to enter the house. "For most people the self is a fragile and vulnerable entity; we wish therefore to envelop ourselves in a symbol-for-self which is familiar, solid, inviolate and unchanging."2 The home becomes the vehicle for presenting one's competence to the world at large. Furniture is often chosen for its style and good looks rather than for accessibility criteria. This
fact also reflects the need we all have to express our personalities and identities in our personal surroundings. Wall-to-wall carpets were installed in one home after being tested with the wheelchair - even though it is counter to all the standards.


2. Ibid, p. 143.
MAINTENANCE

Narrow hallways and narrow doors combined with frequent passage by people in wheelchairs gives rise to a maintenance problem not shared by other households. Foot rests are the most likely part of the chair to collide with the walls and doors or cabinets and furniture. Wheels also contribute their share of scuff marks. The zone between 4" and 18" above the floor receives most of this abuse. Another zone that receives extra soil is the wall and furniture in the zone between 20" and 30" above the floor where people's hands push to gain a bit of extra guidance for going around corners or for maneuvering in a tight space. Every house except the one designed with wide corridors and doors had its catalogue of scapes. Even in that household the kitchen cabinets were replaced due to the scuffs from too many "side-saddle" approaches.

Some guidelines recommend kickplates for the doors, yet none of the case study families had them installed.
ACCESSIBILITY SYMBOL

Standards
In the United States, housing funded in any part by federal monies must comply with the Minimum Property Standards (MPS) of the Department of Housing and Urban Development. Any housing that is designed under the MPS for the physically handicapped must comply with the American National Standards Institute Specification for Making Buildings Accessible to and Useable by Physically Handicapped People (A117.1). The latest version of that standard is dated 1977 and is not yet officially adopted as the national standard for all construction.

To meet the MPS, elderly housing must have 10% of its units with accessible bathrooms and half of those units must have accessible kitchens. Because the ANSI standard is required in the MPS, it is the basis of analysis for this study. In BUILDINGS WITHOUT BARRIERS there is an excellent chart that compares dimensional requirements for 13 different standards and state building codes.

It is the intent of any standard to set its requirements in such a way that the greatest number of people are accommodated without having to design for every specific case or for the maximum condition. The case studies presented here indicate that a large number of chair-bound people can live independently with their families in homes that do not meet the ANSI standard. It is also clear that a large number of housing units would be adaptable if certain basic accessibility criteria were met.

Proposed here is an analysis of the ANSI standard that prioritizes adaptations into three categories: minimum, acceptable and adapted.

Such a set of standards should serve the needs of a large percentage of the chair-bound population while enhancing the environment for the ambulatory as well. "You have all these regulations about the handicapped, who are five percent of the population. What about women who are fifty percent of the population? We now have ramps in buildings because there are a few handicapped people - when women with shopping carts and baby carriages have been pulling those damned things up steps for generations."
from the study of families in their homes as well as from the anthropometrics upon which the standard is based. In the following analysis, the section numbers are the same as those in the 1977 proposed standard.

6.1.1 Minimum requirement should be that there be safe and easy passage through or past the site for most people with mobility impairments. Adapted requirement would be strict adherence to ANSI section 4 dealing with site development. Designers should keep in mind that with steeper ramps and curb cuts, fewer people will be able to negotiate the slope and that untextured slopes can be hazardous for the blind.

6.1.2 Minimum standard should be that there be an accessible path from the entrance most convenient to parking to all common spaces and to the entries of the dwelling units. Acceptable standard would be an accessible path from the most convenient and the main entry if they are different. Adapted standard would be that all entries are accessible.

6.2.1.d For families with children, inaccessible bedrooms should not be allowed even for the minimum standard. For households of unrelated individuals, inaccessible bedrooms may be appropriate.

6.2.2 Width of circulation space 36" clear width for all corridors.

6.2.3 Doorways Doors should all be 32" clear opening positioned so that an average electric chair can negotiate the turn (use 5.2 of the ANSI standard as a guide) for all standards. Case studies indicate that narrower door openings are negotiable with some difficulty, especially if coupled with a narrow hallway. Closet doors may be 30" clear without becoming inaccessible, but bathroom doors should never be less than 32" clear opening.

6.3 Kitchens
Case studies show that a large percentage of chairbound adults can operate in a standard kitchen if hardware and appliance controls are within reach and do not require a grasp or a pinch to operate. Minimum standards would require these controls plus floor space large enough to make a 180° turn. Acceptable standards would add removable cabinets under the sink and range top plus a pull-out board at 30" above the floor. Case studies indicate that knee space under the sink and the ability to see into pots on the stove are the most critical issues for those who find stand-
ard kitchens too awkward to use. An adapted kitchen would meet the entire section 6.3 of the ANSI standard.

6.4 Residential bathrooms
Minimum standards would require clearances as in the ANSI standard with the goal of making transfers easy and turns smooth and unobstructed. Also the cabinets under the lavatory should be removable. The medicine cabinet and mirror should be within reach.

Acceptable standards would require that the tub controls be at the back wall rather than at the foot. Grab bar reinforcements would be added with the requirement that all towel rods, etc should withstand 250lb load for five minutes.

Adapted standards would include a roll-in shower.

6.5 thru 6.9 should be a part of all standards.

A note about storage: Where both ambulatory and chairbound people are using the storage space, the maximum shelf height can be raised to 78" (assuming it is not elderly housing). Similarly window controls need not meet so stringent a standard for ease of opening, yet the standard does not inconvenience the able-bodied.

Ideally ALL new housing should meet the minimum standards enumerated here. Such a policy should give a much greater choice to the majority of the disabled population. Just what percentage of new units should meet the acceptable or adapted standard is hard to define due to the difficulty in assessing the need.

It may seem politically naive to advocate a prioritized standard yet conceptually it seems workable in that more units would have to meet a less strict standard and more housing would become accessible to the less severely disabled.
### ANSI standard items

<table>
<thead>
<tr>
<th>Feature</th>
<th>Family 1</th>
<th>Family 2</th>
<th>Family 3</th>
<th>Family 4</th>
<th>Family 5</th>
<th>Family 6</th>
<th>Family 7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accessible path car to door</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Mailbox in reach</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Accessible storage</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Grab bars</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Hallways (36&quot; clear)</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Doors (32&quot; clear)</td>
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<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
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<tr>
<td>Kitchen counter appropriate height</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Accessible appliance/equipment</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Toilet clearance/height</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Sink height/knee space bathroom</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Accessible medicine cabinet</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Mirror appropriate height</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Tub accessible/controls</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Shower accessible/controls</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Accessible electrical outlets</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Refrigerator volume within reach</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Ease of opening windows</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
</tbody>
</table>

- ○: Existing feature, no need to adapt
- ●: Feature adapted
- X: Neither adapted nor easy to use
- X: Feature not needed

**Figure 5. Compliance of Case Study Homes to the Proposed ANSI Standard A117.1**


Lawton and Nahemow define adaptation level as the state of competence and environmental press being in balance. The case studies presented here indicate a far more dynamic system. Figure 5 shows a schematic diagram of the "dynamic competence equilibrium model" - where equilibrium is defined as constant adjustment rather than balance. The arrows indicate the interactions between the primary elements. Figure 6 shows other relationships between the elements.

In addition to Lawton and Nahemow's collection of abilities (cognitive, psychological adjustment & physical health) this model defines competence for the chairbound individual as the extent of motor function, coping strategies, level of physical adaptation. Those factors that contribute to the sense of individual competence, and that individuals make decisions about in terms of their sense of competence, are wheelchair specifications, adaptations to their home physical environments, level of family support and paid aides. These factors are parallel to the concept of environmental press. Obviously there is a fit/adjustment between the specifications of the wheelchair and the circulation spaces in the home. Most of the case study participants with narrow doors and hallways have chairs that are as narrow and short as possible. One widened all the doors in order to solve the problem.

There is also a very strong interaction between family supports and adaptations to the home environment. There is the question of the image that the family wishes to present, their norms and values, their activity patterns, their roles, their economic resources and the willingness and/or ability to assist the chairbound family member. The amount of family support available is also a factor is the decision about hiring aides. Most paraplegics do not need personal care attendants, even when living alone. Higher level quadraplegics are more likely to need assistance on a daily basis. These interactions and adaptations are carried out in a context of rehabilitation philosophy: the level of competence that is expected to be achieved, the attitudes about normalcy and the information sought out to implement decisions. Economic resources also play a part in the decision process. The lack of resources can severely constrain physical adaptations and thus
FIGURE 6. DYNAMIC COMPETENCE EQUILIBRIUM MODEL
throws a larger burden on family supports and the social service system. It appears that even with limited resources, dependence upon the social service system is less when a chairbound person is living independently with a family or with unrelated others than when institutionalized.

The case studies show a wide range of choices made within this model's boundaries. All show a pattern of increasing competence over the years - either through physical adaptations or changes in their behavior. Other cases might show a different pattern if the participants were chosen differently, but this author doubts that the majority of chairbound individuals is satisfied to maintain the status quo rather than moving toward their maximum performance potentials.

As one of the participants in the case studies put it, "I can't be soft on myself, I have to keep in shape!"

![Figure 7. Relationships of the Equilibrium Model](image-url)
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Develops a distance-regulation model of family interaction with 5 components: 1. sub-systems of families and their interfaces, 2. access dimensions (space, time, energy, plans and strategies) and mechanisms of family process, 3. target dimensions (goals), 4. family process types and, 5. interactional system of four player parts (mover, opposer, follower, bystander). The book is useful for understanding the house/role interactions of a family.

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TO: Donna Duerk
FROM: Bernard S. Gould
DATE: March 21, 1980

SUBJECT: Enabling Environments: Post Occupancy Evaluation of Single Family Housing for the Physically Disabled

APPLICATION NUMBER: 1043

Your application has been approved by the Committee on the Use of Humans as Experimental Subjects at its meeting on March 20, 1980. This approval is valid for one year. It is expected that you will notify the committee of any change in your protocol during the course of the year, and also inform the committee when your project is terminated.

xc: Sandra Howell
William Porter
Hello,

We are interested in conducting a study of the architectural features of homes that have been designed or renovated for families which include one wheelchair-bound adult. It has been suggested that you might be willing to participate.

This study will generate information to be used for a teaching case study to be conducted by the Laboratory of Architecture and Planning at MIT which will be authored by Ms Donna Duerk and Mr Tip Thiboutot. The information will also serve as the basis for Ms Duerk's Master of Architecture thesis.

Your participation will involve about ten hours of your time spread over a two week period. The ideal schedule would be for Ms Duerk to visit your home on a weekday evening for about two hours - to fully explain the study and to ask some initial questions about how you planned your home and how it works for you. Between the first and second visit you will be asked to keep a diary of some of your daily routines, specifically those activities related to your use of your house - even if it has already been adapted. This should take no more than four hours total time. The second visit should take place on a weekend during daylight hours so that photos might be taken. At this time we would also discuss the diaries and ask you to respond to a final set of questions. This visit should take no more than four hours. Shorter visits can be arranged to suit your schedule.

We hope that you will be able to participate since we feel that the information you have to share will be very valuable to our study and will be useful in sensitizing designers to the issues of independent living. If you do not wish to participate, could you suggest another family that might be interested? If you do wish to participate, will you please call Ms Duerk at 253-7648 during the day, or 738-5323 during the evening? A quick response would be greatly appreciated. Thank you for your consideration.

Sincerely,

Donna P Duerk
Tip Thiboutot
THESIS/CASE STUDY RELEASE FORM

I understand that Donna Duerk is doing a thesis for a Master of Architecture in Advanced Studies degree at MIT and that she is to be co-author of a teaching case study for the Laboratory of Architecture and Planning at MIT with Tip Thiboutot. I also understand that the study is focused on our use of our house and that the information gained may be useful in teaching designers about designing homes for families with a disabled member.

I agree to participate in the study voluntarily and understand that I may withdraw at any time that it proves to be necessary, giving notice beforehand. I understand that I will not be compensated for my participation.

I hereby authorize the following items by placing my initials in the appropriate boxes:

☐ I authorize the information I give to be published by the authors or the LAP for Ms Duerk's thesis, the LAP case study, for articles and lectures.

☐ I authorize my home to be photographed and for the photos to be used in the thesis, case study, articles and lectures as above.

☐ I authorize photographs of myself to be made and to be published in the thesis, case study, articles and lectures as above.

☐ I authorize photographs to be made of my children and for them to be published in the thesis, case study, articles and lectures as above.

☐ I authorize my name to be used in the text and captions of the thesis, case study, articles and lectures as above.

☐ I do not authorize my name to be used, but I do authorize a pseudonym to be used in the text and captions of any publication resulting from the study. I prefer ______ as my pseudonym.

☐ I understand that I will be able to review all the photographs before publication if I so desire. I do not want to review the photographs before publication. I understand that only those photos that I approve for publication will be used for thesis or case study and for all future articles and lectures.
I understand, that in the event of injury resulting from the research procedure, medical care is available through the MIT Medical Department. The costs of that care will be borne by my own health insurance or other personal resources. Information about the resources available through the MIT Medical Department is available from Lawrence Bishoff at 253-1774.

There is no compensation for possible injury, either financial or insurance, furnished to research subjects merely because they are research subjects. Further information may be obtained by calling Kimball Valentine at 253-2822.

Signed ____________________________ date ____________

Signed ____________________________ date ____________
INTERVIEW FORMAT

1. Names of interviewees __________________________ ages ____________
   Names of children __________________________ ages ____________
   Age at disability ______ age at marriage ______

2. Description of disability—trunk balance, hand, arm, finger, hip and thigh strength/control. Do you have occasion to stand for some items?

3. Specifications of home wheelchair-(s)

4. Factors in choosing this house—build or remodel? search process? criteria—when did you move in?

5. In what ways is this house house like others you have lived in? In what ways is it different? What are the other houses like that you have lived in since the incidence of the disability?

6. What changes/design features did you specify before moving in here?
7. What changes have you made since moving in?

8. What changes are yet to be made?

9. What information did you seek out in order to know what was available? What was your information search process? What were your sources?

10. What discoveries have you made about the ways you use your house since you moved in? Any happy surprises?

11. What was the process for choosing your furniture? What were the criteria?
INTERVIEW FORMAT  P III

12. What are the major family activities that happen in the house? Outdoor family activities?

13. What design features did you consciously decide not to include in your house? Why?

14. In what areas of the house do you spend most of your time? What are the activities in those spaces?

15. What are the areas of the house that you spend the least time? Why?
DIARY INSTRUCTIONS

Please describe your typical patterns of behavior for the activities listed below with as much detail as possible, taking care to emphasize the interactions you have with furniture, equipment and the elements of your house. Please observe yourself for one or two days so that you notice your most routine actions then begin to take notes in the diary. Please include all repetitious activity in its proper sequence. A notation of a particular day's sequence of activities or your memory of the most recent applicable event will be sufficient. Please note the time as accurately as possible or give your best estimate of the average amount of time you spend on a particular task.

Activity I - getting up and out

Please describe your morning routine from the time you wake up to the time you leave the house, start your work or begin your usual day's activities after breakfast.

Activity II - food preparation/dining/cleanup

Please describe your involvement in the activities of preparing your evening meal, eating it and cleaning up afterwards.

Activity III - entertaining

Please describe a typical evening or weekend event when one or more friends came to visit (a description of the most recent event will be fine).

Activity IV - caring for children (Skip if not applicable)

Please describe your usual evening routines for caring for and interacting with your children after the evening meal until their bedtime. If your major interaction with your children is on the weekend, please describe a typical weekend afternoon.

Activity V - leaving/being left alone

Please describe the activities and preparations required for leaving/being left alone for a period of 6 hours or more or for overnight.

In your diary notations, please use the following format as an example. I am interested in the necessary relationship between the physical environment and your daily routine. The following is my morning activity diary as an able-bodied single parent.

<table>
<thead>
<tr>
<th>ACTIVITY I - getting up and out</th>
<th>COMMENTS</th>
<th>TIME</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clock radio wakes me up, I doze for about half an hour</td>
<td>6:50</td>
<td></td>
</tr>
<tr>
<td>I roll to my back, throw off the covers, sit up and throw my legs over the side of the bed. I stand and walk out of the bedroom thru the kitchen to the bathroom.</td>
<td>7:20</td>
<td></td>
</tr>
<tr>
<td>I walk to the toilet, turn my back and sit down. When I am finished, I get up turn to the</td>
<td>The bathroom is large but without adequate storage. 7:22</td>
<td></td>
</tr>
<tr>
<td>I roll to my back, throw off the covers, sit up and throw my legs over the side of the bed. I stand and walk out of the bedroom thru the kitchen to the bathroom.</td>
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<td></td>
</tr>
</tbody>
</table>
sink, take two steps and face the mirror. I then brush my teeth, wash my face and take my vitamins. (If I choose to take a morning bath I do so before I brush my teeth etc.)

*If my daughter is not awake yet, I wake her as I walk to my bedroom.

*In my bedroom I select my clothes from closet and dresser and lay them on the bed. I take off my nightclothes, put on my underwear, sit on the bed to put on socks or stockings. I stand to put on deodorant and perfume.

*I put on the rest of my clothes and stand in front of a small mirror on top of my dresser to put on makeup.

*If my daughter is not yet awake I try again

The wakeup routine may be repeated once or many times.

* I then go to the kitchen to make breakfast (toast and grapefruit)

* Last minute chores and routines such as feeding the cat, making lunch straightening the desk, and finding my papers for the day are next and in no order. These chores take me from the kitchen to the living room and back a number of times, in no certain order.

* Last minute check for glasses, keys, books, purse, coat, hat & mittens. The hall closet & hall are so small that I often leave my coat in the living room.

When I rush, I can leave at 8:00, if I add reading a paper or some last minute chores I leave as late as 9:00 or 9:30.

Thank you for your energy.