INVENTORS, EXPLORERS, EXPERIMENTERS: HOW PARENTS ADAPT HOMES FOR CHILDREN WITH MOBILITY PROBLEMS

by

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ABSTRACT:

Parents rearing children with severe and complex medical problems and the professionals who serve them find themselves facing novel challenges. Twenty years ago such children would not have survived, and if they had, would probably have been placed in an institution. Each year the life expectancy of these children increases and policies of normalization and deinstitutionalization have increased the liklihood that such children will remain at home from birth through latency to young adulthood.

This study uses the case study method to examine the efforts of six families who removed architectural barriers in their homes. Each was rearing a child between the ages of 6-14 with severe mobility problems caused by Spina Bifida Myelomeningocele. The qualitative data was obtained from in-depth interviews, from photography and drawings by family members, from examining plans and from questionnaires. The researcher joined the Massachusetts Spina Bifida Association and attended their meetings for approximately three years.

The focus of the enquiry was on the family's routines, child-rearing practices, concepts of an "ideal home," and how it made decisions during crises situations and routines. With regard to organizing the architectural adaptations, family members were asked to recall what caused them to initiate changes, where they obtained information, how they made design choices, how they had their designs built, and what the effect was of architectural adaptations on family life. Key professionals who work with such children were also interviewed.

Findings indicated that parents faced practical and psychological challenges. They cited their own lack of technical knowledge, time, and money. It was found that medical professionals had little interest in the home, and no expertise in making architectural adaptations. No parent was asked how they were managing at home.

Adapting the home means accepting the permanence of the disability and making the family's disability public -- stigmatizing the house --

and thus its occupants. In general, parents postponed removing architectural barriers until a crisis occurred, however, when architectural barriers were removed; parents and children perceived that they had increased control over their lives, parents' medical problems abated and they expended less time and effort on daily chores.

Children who had been involved in making their homes barrier-free began to have some ability to transfer this knowledge to other environments such as their schools.

Thesis Supervisor: Dr. Gary Hack, Ph.D.

Title: Professor of Urban Studies,
Chairman of the Department of Urban Studies and Planning

DEDICATION

I DEDICATE THIS STUDY TO FAMILIES EVERYWHERE WHO FACE

THE CHALLENGE OF LIVING WITH A PERSON WITH DISABILITIES.

This study was possible only because a group of parents from the Massachusetts Spina Bifida Association were willing to collaborate. They donated their time and energy in the hope that the research would help families similar to their own, so that their lives would become easier. Families were open and sharing. They revealed themselves so that there were times when they and myself were near tears. They introduced me to a new world, and for this I am grateful. This knowledge will influence me for the rest of my life. The names of families have been changed to provide some degree of anonymity.

I DEDICATE THIS STUDY TO THE MEMORY OF KEVIN LYNCH, A VISIONARY

Kevin was instrumental in my being accepted at MIT, and it is with sorrow that I find myself in the position of being the last student for whom Kevin acted as advisor and mentor for a doctoral thesis. What a loss it is that others will forego the privilege of meeting with him on this basis. I appreciated his directness, his sense of humor, and his distaste for unnecessary complications. His advice was instrumental in helping to shape the form of the thesis, and, while his insights echoed through my mind and influenced my choices while writing, had he lived, this dissertation would have been much improved. He constantly urged that I keep close to the data, and stressed that writing is work which can best be accomplished by sitting down each day for a certain number of hours. His attitudes will guide my future work.

ACKNOWLEDGEMENTS

I feel that I am the most fortunate of women, for I have had the support, mentorship, and love of outstanding people. That I have completed a Doctoral degree is a source of wonderment to me, for twelve years ago I had not even given the world of academia a thought.

So many people enabled me to negotiate this passage successfully that it would be difficult to name and thank each of them individually. However, there are certain people who made this endeavour possible; they cheered from the sidelines, and had confidence during the darkest moments that, indeed, I could make it. I hope that they will share in satisfaction of this project now completed.

To my committee who guided me through this task, I am indebted. Each provided a unique perspective. They have helped me to learn to conceptualise issues and to acquire a certain intellectual breadth. It was Florence Ladd who urged, during my first year at MIT, that I focus my studies on vulnerable populations, and were it not for her, I would not have pursued this line of enquiry. Jim Callahan helped me focus my research questions for this population and was interested in my taking a systems approach. Kevin Lynch insisted that I be true to the data and myself. He once jokingly said that it was fine to have my head in the clouds as long as my feet were firmly planted on the earth. Gary Hack, as Chairman of the Committee, encouraged, goaded, and stimulated at the appropriate stages. He knew when to treat me as a student and when to respect me as a professional. He was a fine mentor. The inadequacies in the work are mine.

While working on this dissertation, as a Fellow at the Joint Center of Urban Studies of MIT and Harvard University, I benefitted not only from financial support and "home," but also from the intellectual stimulation provided by a fine group of people who take their work seriously rather than themselves. My thanks go to all the Fellows, Faculty and Center staff. My especial appreciation to Carol Scanlon, to Angeline Ferreira and Jennifer Hitchcock. Carol patiently explained (and explained) the intricacies of word processing to me, she also rescued floppy discs in danger of turning into gibberish; Angeline and Jennifer painstakingly proofread the final document.

The Polaroid Foundation provided a grant of materials which enabled parents to document their images of home, and allowed me to experiment with a somewhat new research tool. Finally, a much appreciated grant from MIT's Department of Urban Studies and Planning enabled me to finish the study sooner rather than later.

Good friends make life worth living. The empathetic consideration and tutoring of my friends and family was invaluable. Each of the following helped: Susan Schmidt Dibner, Barbara Mehren, Stanley and Cyrenne Baretto-Morse, Ray Lifchez, Alice Eiseman, Vera Kilstein, Gloria and Stanley Rosensweig, Janice Rossbach, Ivor Freeman, Dianne Goodchild, and my thesis writing group at MIT. These people read drafts when the writing was in terrible disorder. They challenged my

ideas and helped me to think and to write more clearly, and Barbara rescued me by expertly drawing the plans when time ran out.

I am indebted to my parents, who showed by their actions (and continue to do so) that it was important to serve others; that tasks when undertaken be completed to the best of one's ability; and that it was important to make a contribution to the world. Were my mother alive, I wonder what she would make of this endeavor?

Finally, to my immediate family; Harold, Shara, Adam and Ian, who bore the brunt of this trial by fire, thank you. Because of this dissertation, life at home changed. Harold was always supportive, always lovingly concerned. He took on unaccustomed roles and showed great flexibility in all matters. His photographic expertise made the difference to the appearance of the document. Shara had a valued clarity of thought and a special wisdom and friendship. Adam and Ian warned me to hurry up with this project, for soon I would be too old to work. Words seem inadequate to express my feelings for them, for I have expended our resources of time, energy and money when all were in short supply. Home life will improve, I promise.

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Introduction

The pale Spring sun edged its way around the clouds to warm the glass enclosed area. I remember it as if it were yesterday, five or six youngsters and two adults sat in a ragged circle discussing plans for the summer vacation. Occasionally someone would move in or out of the circle either to make a point or to see the face of the person who was speaking. "Well for most of us" Tom explained, "going home is all right, but once we're in the house we can't get out and even inside maybe we can get to one or two rooms. Only Alice and Jim have homes they can really move around, and that's because their Dads have built ramps and made a lot of other changes." All the children were residents of the Massachusetts Hospital School in Canton, and this was my baptism for encountering children with severe disabilities. I learned back then in 1974 that although the students might not be "permanent residents" at the facility, perhaps 2% of their homes were barrier-free.

This was not the only experience that influenced my decision to study the environmental design needs of parents rearing a child with severe disabilities. My selection resulted from personal experiences both within my own family and in graduate school as well as during professional encounters. The research topic was and is a subject I find compelling, so much so that I had considerable concern that I would be incapable of doing the subject justice.

Let me identify some of these influences. A course taken in 1979 with Jay and Helen Featherstone,[1] introduced me to the needs of people with differing disabilities as well as those of their families. They pointed to societies' treatment of such populations and raised questions in relation to the ethical issues of disability. The literature on their reading list rarely referred to the physical setting, yet, reading between the lines, it was apparent that "place" made a difference.

To meet the requirements for their course, I chose as a project, to examine our home environment in terms of our family and the particular problems which arose in trying to raise an 8 year old son with severe learning disabilities. An interdisciplinary team of a sociologist, an architect and I collaborated closely to examine the functions that seemed to be most problemmatic for our son (and family) and to redesign the physical setting to encourage desired behavior (Lewis and Dibner, 1983).

Behavior measured before and after the design showed remarkable changes and the intervention changed the behavior not only of the child, but also of our other children, and my husband and I realised that we too needed to change our actions. Because I was both researcher and parent, I experienced the intervention subjectively, but needed to step back and view it objectively. I began to reflect on the effects of being interviewed. Frank discussions with the professional team provided insights which have proved useful when working with parents, and certainly during this present study.

Over time my definition of environment grew to include the physical setting, natural or built; the social structure that exists within it; and the surrounding culture and geographic context. All these elements combine to produce what individuals perceive as "environment." While it is possible to, and much research does choose to, select a single variable or a small number of variables to explain environment, I would argue that such a simplification reduces the liklihood either that the problem will be accurately defined, and therefore reduces the probability of generating viable solutions.

Housing designs affect behavior in obvious and subtle ways. Design affects the manner in which homes may be furnished (Howell 1978). The configuration of buildings impact how people arrange their schedules and activities (Kuper, 1976), impinge upon the amount of play and social interaction enjoyed by young children in high rise apartments (Becker, 1975), and on neighboring (Festinger, Schachter and Back, 1950). People with obvious limitations are more noticeably affected by the physical setting, environments inhibit or expand their ability to perform (Lifchez and Winslow, 1979; Howell, 1976; Ostroff, 1978; Schneekloth 1982).

Professional encounters as an environmental analyst and planner brought me into contact with a wide variety of people with special needs including elderly people, and people with physical and mental disabilities. All these experiences lead me to endorse the findings of others in the field, that people with disabilities are especially in need of supportive environmental design. Although an especially insightful experience came from teaching a course on home environments to parents who were raising a child with severe disabilities, it was the layering of all these experiences that re-emphasized the need to approach the environment as a multi-dimensional and complex entity, and to place particular emphasis to the <u>process</u> used to create environments.

Finally, it was during the preparation of a graduate course on "Housing for People with Disabilities" that I noted the literature invariably referred to adults' needs. Wording of housing regulations used the nomenclature of "persons," which did not preclude children, but in practice it seemed that children were not discussed as possible users of barrier-free housing.

In Massachusetts for example, public housing authorities build a small percentage of units for people with disabilities. When The Back of the Hill Housing, (Mission Hill, Boston) received an application from a family with a child with disabilities in the late 70's, they had to petition for this family to be accepted as tenants of a barrier-free unit. The prime user of barrier-free housing had in the past always been adults. It was the management's understanding that they were the first housing development to make such a request of the housing authority.

Barrier-free housing appears to be a commodity provided mainly for adults over 16 years of age capable of, or with the potential of becoming income producing. In addition it appears that most services such as providing personal care attendants are also established primarily for adults. There is an unspoken assumption that parents of children with disabilities will automatically function as unpaid personal care attendants; or that parents will manage to remove architectural barriers by themselves, when and where they exist in the home; or that perhaps architectural barriers are of less importance for a child. Is it purely an oversight, or are these issues disregarded because of the limitations in the State or Federal budgets? All my observations of family life, information provided personally by parents and by the children and literature written by parents urge that a range of supports are necessary. Featherstone (1980) calls them margins of support, I suggest that removing architectural barriers in the home would be a significant one. An adapted home may be more valuable in the rehabilitation of an individual than increasing physical therapy. Too frequently individuals spend hours in physical therapy trying to learn a particular task such as climbing steps. Clients and physical therapists expend time, energy and psychic energy in doing this. Removing the steps would allow time for individuals to concentrate on more interesting, stimulating activities.

I would now like to turn to what some view as a critical issue, the development of a national family policy. There are those who urge for the establishment of a national family policy, to give direction to U.S. social policy at the Federal level. Kammerman and Kahn (1978) defined family policy as meaning everything that government does to and for the family, they urge that policy have the articulated mission of "family well-being." Were the well-being of families in all their diverse social configurations provided with support, then families similar to those in this study would certainly benefit. The lack of such a policy is seen as detrimental to all children and their families and particularly harmful for children such specialized needs and their families.

In the past, U.S. policy makers have hesitated to violate the sanctity and privacy of "the family," and at a White House Conference in recent years, representatives had difficulty in defining this social unit. Traditionally, the State and the individual have been two "poles" of concern, and the argument has been how to distribute power between them, it has, however, been suggested that another competing pole "the family," a unit always outwardly respected but sadly neglected, could and should be interjected (Myerdal, 1976).

Those individuals who support that the U.S. have an explicit family policy point out that this country is the only industrialized nation not to have such a policy, and yet countless government decisions are made explicitly to affect family life, while others do so implicitly (Moynihan, 1965; Myerdal, 1976). Daniel Patrick Moynihan reiterated this view, that a national policy is required during the 1985 Godkin lectures at the Harvard Kennedy School of Government:

> "A national policy need only declare that it is the policy of the American government to promote the stability and the well-being of the American family; that the social programs of the federal government will be formulated with this object in mind..." the concerns would include those "... not of the American family, but rather of the great range of American families in terms of regions, national origins and economic status" (Costello, 1985).

This issue is, of course a political one, and Marion Wright Edelman spokesperson for the Children's Defense Fund, identified the fact that, although the image of the needy child is a powerful one, because children have no clout, it is relatively easy for a politician to cut out programs for children despite the negative impression that such a vote may have on his or her record. Edelman is quoted as saying, "Children's issues fall through the cracks. Everyone's kind of for them, but never enough." (Kuttner, 1982, p.51).

Failure to consider "the family" has had its effect in the manner in which legislation and services have been provided for all children and their families. Services and programs for all children are scattered throughout dozens of agencies and covered by numerous pieces of legislation. Fragmentation of services causes frustration for any average family attempting to obtain assistance, but it creates a particularly stressful situation for a family raising a child with severe disabilities when personal resources are stretched thin.

A sketch of the historical context will provide a backdrop to understanding the situations families raising children with disabilities now contend. Only a few years ago a study of this nature would have been perceived as a "non-issue," for it would have been the exception, rather than the rule for a child with severe disabilities to live with his or her family. Over time, however, the social context has changed, and, as a result of the policies of deinstitutionalization and normalization the accepted placement of the child is at home, within the family. In the past too, most children with severe disabilities did not survive past early childhood, or after a serious traumatic accident or acute illness. Parents and professionals therefore did not have to meet the challenges present today.

The Altered Social Context

Families raising a child with severe disabilities represents a relatively new phenomenon; 15-20 years ago it would have been more usual for parents to have been advised to place a child like this in an institution. This reversal from institution to home as being the preferred placement for the child (or person with disabilities) is the exact opposite of what happened in the Jacksonian era. This section briefly traces the pertinent historical events that occurred from that time.

From the 1820's onwards there was a turnabout in social practices. "Americans began to construct and maintain institutions for the deviant and dependent members of the community." (Rothman, 1971). This building of institutions of all kinds, -- penitentiaries, insane asylums, almshouses -- drew attention from liberals abroad such as de Tocqueville, who visited the states to study the penal system and wrote of The Democracy in America 1835-40. These institutions were seen as models for the world.

If we ask why American philanthropists chose in the nineteenth century to use institutions as a "reform," it is possible to generate various reasons; however Rothman states that there was no evidence that the institution was a logical device to counteract earlier treatments for people with differences. It was not the result of a medical break through, nor was it an inevitable response to situations generated by a newly formed industrialized, urbanized society, which might consider coercian rather than benevolence to be at the heart of the movement. He suggests we should view the establishment of institutions within the prevailing social context. He reasons that it was an attempt to enhance the stability of society, to ensure a reasonable society, to achieve balance in the new republic, and to eliminate long standing problems.

The intent of institutions initially was to rehabilitate inmates and their new status would set an example to the rest of society, indeed the world. The well ordered institution would model the correct principles of social organization both morally and architecturally,[2] and this would promote and insure the integrity and glory of the new republic. As we now know, this innovation fell far short from this vision.

A retrospective view shows that from the mid 19th century until the 1900's, the approach towards people with disabilities veered from making the deviant less deviant, to sheltering the deviant from society. During the first quarter of the 20th century, a new perspective, namely, a fear of individuals significantly different, led to the belief that it was necessary to protect society from deviants, for they were a social menace. Such an altered perception did not happen uniformly or simultaneously across the country, but these were discernable patterns, so that by the early 1900's the institutional system had erupted into sprawling facilities managed by huge staffs. Society, in fostering and institutionalizing such a system had created an entity that gathered its own momentum and "demanded" continuity (Goffman, 1961; Rothman, 1971). It had become an industry which commanded political clout and patronage. It was an entrenched system, difficult to change.

Around the middle of this century new themes emerged. Principles known as normalization and deinstitutionalization were concepts developed in Scandinavia which stated that such people with mental disabilities were individuals, people with preferences and unexploited potential (Wolfensburger, 1969).

Normalization: The normalization principle had the goal to make available patterns of life, that is, daily routines of work, recreation, and special celebrations. It also contended that individuals would benefit from living within homelike physical settings. Such surroundings would promote personal growth (Nirje, 1969). It was found that individuals with severe mental disabilities were capable of learning and acquiring skills when in homelike environments (Bayes and Franklin, 1971). Normalization has also come to mean that people be trained to behave as close as possible to accepted behavioral standards (Wolfensberger, 1972).

While there are many definitions of normalization, the Massachusetts Developmental Disabilities Council, in a pamphlet still being distributed in 1985, defines normalization as:

> The philosophy that persons with disabilities should have available to them patterns and conditions of daily life which are as close as possible to the patterns of the mainstream of society, in settings which are least restrictive of their personal rights.

Deinstitutionalization: This was seen as the solution that would enable people to live "normally." Essentially it was the removal of people from institutions into community based, small scale "family" sized units. It was a contrast in living. People moved from custodial dependence to programs which emphasized maximum independence according to the person's capabilities. People's removal from institutions was perceived by proponents of the principle as being both socially and economically viable when compared with the costs of transforming the degrading institutional environments into humane "homelike" settings.

In Massachusetts, however, large sums of monies were poured into making the buildings less institutional, and for training programs for staff, which reduced monies available for community based services. Since the 1970's, Massachusetts has had a policy of no admittance to the State schools and this has been more or less maintained. According to one Massachusetts Department of Mental Health official, in 1983-84, 45 adults were admitted and no children.[3]

This policy has resulted in the need for creative approaches to deal with the dismantling of the system (and the re-establishment of an alternate one). The outcomes of deinstitutionalization has been that the more fortunate of the former inmates have learned to live more normalized lives. They moved into congregate living situtions, supervised apartments and perhaps after time, into their own places. The less fortunate have been "dumped" into communities with too few organized supports. Thousands of these individuals now wander homeless through towns and cities across the country, many fall prey to ruthless individuals who see that they can make a living off these people's Social Security Income checks.

The overall principle of deinstitutionalization was introduced because parents and a few professionals shocked at the inhumane, deprived environments existing behind the walls of the isolated institutions set out to change the situation even if it meant filing class action suits. They realised that the large scale institutions [ware]housing this population had failed its residents [inmates], and invariably encouraged maladaptive behavior (Goffman, 1961). But why did they begin to make their bid for altered conditions when they did?

The political activism of the 50's led to an awareness by minority groups that they had much to gain by alliances. Coalitions formed across disabilities. People with disabilities joined the Civil Rights movement or became involved in the Welfare Rights Organization (to gain entitlement to income, education and medical benefits). This heightened awareness among people with disabilities developed into the Disability Rights Movement. Wounded American war veterans were particularly vociferous in demanding their rights. They were disabled because they had defended their country, did not America owe them the opportunity to a decent worthwhile life? They wanted a normalized life outside an institution.

If we trace the years when groups were founded, we can observe the progression of consciousness within the movement. 1958 saw the formation of the National Congress of Organizations of the Physically Handicapped and in 1974 the American Coalition of Citizens with Disabilities. People with disabilities had become a constituency aware that its civil rights had been violated. President Johnson's vision of "The Great Society," his negotiation of the passage of the Civil Rights Act, 1964, and the Voting Rights Act, 1965, held a promise which fired the imagination of all Americans, including people with disabilities.

When adults with disabilities found that their needs were not being provided for, they staged their own march on Washington in 1972 and sit-ins in government offices. The group gained support for the Rehabilitation Act of 1973. PL93-112 was passed, a law frequently described as the Civil Rights Act of the Handicapped. Principles of equal opportunity, non-discrimination, pursuit of happiness, freedom of choice and individuation were now promoted for a formerly disregarded population.

The law mandated this population's right to education, to housing to public facilities and employment.

Removing architectural barriers: While all minorities face social barriers, people with physical disabilities are confronted with physical barriers. Physically disabled people, for example, are unable to climb stairs, use ordinary bathrooms, or drink at water fountains which are not scaled to their needs. Those with other types of sensory disabilities face a constellation of different problems. The outcome has been that the handicapped have been virtually denied access to public facilities. Architectural barriers were and are an impediment to their participation as citizens and redress of this form of segregation was initiated in late 50's. Ten major public laws passed by Congress reflect a changed focus from providing personal adjustment services to people with disabilities to adapting the built environment so that it did not further handicap individuals (DeJong and Lifchez, 1983). Physical barriers were seen as "pervasive in their influence in that they reach to all aspects of the built environment including all building types and the spaces between buildings" (Bednar, 1977, p.1).

The efforts on behalf of people with mental disabilities, therefore, coincided with the social revolution taking place in U.S. society generally. They wanted meaningful, long lasting changes. People with disabilities pointed to the inequities that handicapped them, making them members of a particularly disadvantaged group. Attitudinal and architectural barriers prevented them from reaching their potential. Access to education, homes, employment and housing was extremely difficult and usually impossible. Given this groundswell of opinion it is understand-able that the philosophy of normalization and its accompanying concept of deinstitutionalization (Wolfensberger, 1969) were acceptable and adopted by people with sensory and physical disabilities in addition to those with mental dysfunctions.

In adopting this policy, it was found that there were few models to assist people with critical disabilities to live a normalized life outside the institutions. This became a major area of concern. Merely moving into a barrier-free home was insufficient. Individuals required training, for many had been overly protected by their parents; they needed assistance in coping with certain actions. One group of people with physical disabilities centered on their desire to become as far as was possible, independently functioning citizens, living within the community. Their experiments in Berkeley, California led to the development in the 60's of the Independent Living Movement.[4] There are now many similar centers across America, and three in Massachusetts.

The events discussed above provide the background to the current rationale which makes it more likely that a couple keep their child born with disabilities at home, rather than being urged "to put the child away, for the good of everyone concerned." The parental home is recommended as the preferred residential placement. It is thought the child will benefit from the stimulation and support of a loving family. (However, most parents in the sample population of this thesis were advised by their physicians to place the child in an institution.) How many families are rearing a handicapped child in their homes?

Incidence and Prevalence

Incidence refers to the rate of occurrence of disabilities, prevalence to the overall numbers in the population. A review of the incidence of 11 chronic childhood diseases gave little evidence that a significant change in incidence had occurred (Walker, Gortmaker and Weitzman, 1981). The numbers of children born with severe disabilities has risen because the cohorts of the "baby boom era" are now raising children, these children will be teenagers into the 90's. With an increased life expectancy for children with chronic, a larger number of surviving children with disabilities can be anticipated. After that group of children have become adults, and because of the overall drop in the birth rate, it is anticipated that the number of children being born will drop, and, if the incidence remains the same or becomes lower, then the number of children with birth defects will drop too.

Increased prevalence in part, is due to the fact that "preemies" and "distressed" newborns who are more prone to illness survive (Budetti and Newacheck, 1983). While it is anticipated that within a few years preventative health care measures will reduce the potential numbers of birth defects, and other interventions such as fetal surgery will further eliminate many of the long range medical, psycho-social and economic costs (Fletcher, 1984), this remains speculation. In the meantime, new attitudes and theories as to what is a viable existence means that the infant who without heroic medical measures would have in the past died, now must, under the law, be given medical care to permit survival, not merely be made comfortable until death. Inevitably this will mean more infants surviving with severe disabilities.

Nor should we ignore the unanticipated effects of modern, medical miracles which may inadvertently cause disabilities. For example, the girls who survived the rare metabolic disorder phenylketonuria or PKU now are of child bearing age. A problem has surfaced. Their embryos are assaulted by a high amount of phenylalanine in the mothers' blood so that the baby's brain may be irreversibly damaged before birth (Haac, 1985).

Currently, estimates rather than accurate figures exist as to the total number of children with disabilities and the nature of their disabilities. It appears that the definition of "severe disability" varies, the method of study varies, and different capping ages were used; therefore, it is not always possible to compare figures. The reporting of disabilities at birth had not been required until 1984,[5] and the child with multiple problems may either be categorized under the disability perceived as being the major handicap, in which case it may be difficult to know the exact nature of the child's problems, or whether the child was counted under more than one category. Estimates vary according to the group providing the figures. The numbers of children and the analyses of their abilities and requirements are not computerized at the time of writing.

To illustrate the fact that it is difficult to compare studies, in reviewing various findings we find estimates run from a (high) projection of 2,504,048 children for 1985 (Callahan, Plough and Wisensale, 1981) to a more conservative estimate of one million (Vanderbilt University, 1983). Yet another study provides us with an estimate based on 1970 figures of 1,676,000 children to age 21 who have movement problems or other impairments and 50,000 multi-handicapped children, (apart from those with hearing, visual and speech impairments, learning disabilities, emotional disturbances and mental retardation (Kakalik, Brewer, Dougherty, Fleischauer, and Genensky, 1973)).

This study sample came from Massachusetts and the most recent research conducted on this population used the 1978 Annual Housing Survey to extract estimated figures and came to the conclusion that there were 3,352 or 6% of individuals in Massachusetts 0-18 years of age who needed housing adaptations (Dunn, 1984).

If the incidence of disabilities at birth has remained stable, the <u>prevalence</u> rates have altered because of the increased survival rates. It has been estimated that the prevalence of childhood disability has doubled during the 23 year period from 1958-1981 from 1.7% to 3.8% from the Health Interview Survey. Increased survival rates range from 2-7 fold for children with certain congenital heart defects, and a two fold increase in survival for children aged four-eight years with Spina Bifida[6] (Gortmaker and Sappenfeld, 1984).

In the past, few children with the complex medical problems accompanying a disability such as (spina bifida) survived beyond the first few months. With regard to spina bifida (the disability of the present Sample) the incidence at birth is .7 per 1000 live births and the assumed life expectancy for a child with spina bifida now is that 50% will live twenty years; however, the expectation is that their longevity will increase rather rapidly in the next few years. We should anticipate that many more children with complex chronic medical problems survive to adulthood. Such a prediction implies major impacts on families, professionals of various kinds, on the provision of barrier-free housing. Costs are high.

John C. Fletcher estimated that more than 250,000 American infants, or 7%, are born each year with mental or physical handicaps, and that the economic costs are high. He noted that these figures are difficult to find, and that those generated in various studies are confusing. Fletcher found a National Institute of Health (NIH) report on congenital disorders citing direct costs as being $1.5 billion, and another $1.46 billion in "forgone earnings," or the lost annual earnings of parents and children who would never work -- a large loss to the nation and to individual families.

Parents now bear not only the social and emotional burdens, but also the financial stress of trying to maintain their child at home. Were they to place their child in an institution such as the Massachusetts Hospital School, the charges as of October 1983 ranged from a low of $221.53 per day in a self-care program to $357.23 when children require certain medical attention.[7] Longer survival rates mean that the population includes many more <u>older</u> children and this, in turn, has implications for generating new and varied methods of management. Special efforts are required to deal with the issues attending adolescence and early adulthood. New understandings must be gained, since these young people, their families and the professionals providing health and educational services are functioning without precedents in an altered social context. Participants in the Independent Living Movement feel frustrated when they perceive parents "overprotective" of their children and unable "to let go."

Why Deal with the Homes of Children with Disabilities?

In addition to the overwhelming facts presented in this background, I would like to personally argue that it is important at this point in time to study home environments for families with severe disabilities not merely because they have been neglected but for the following three reasons:

- It is appropriate to give support to parents and families who shoulder unreasonably difficult, permanent burdens and are doing their best under challenging circumstances.
- The home provides an informal learning environment throughout the life cycle.
- A changed social context has altered expectations _by_ people with disabilities and _for_ people with disabilities. Children with disabilities must now be encouraged to live up to their potential so that they take a meaningful role in society.

The logic behind these three reasons can be explained as follows:

a) _Families require support_. This paper does not advocate returning to a system which institutionalizes children for their lifetimes, but points out that previously it was either the State (and therefore the taxpayer) or the parent who paid in part for the high financial cost of the institutionalized child, but the parent did not have to cater to the child's ongoing care. Now parents and families bear the emotional, physical and at least partial economic brunt of the new order. They struggle with their emotions and juggle with scarce family resources (Featherstone, 1980). As parents and families, they must cope with fragmented and often non-existent services (Gliedman and Roth, 1980), and the well-being of the family is compromised when its efforts are handicapped by physical as well as social barriers. Physical barriers "compromise access, [they are] obstacles that limit opportunity, promote discrimination, prevent integration, restrict choice and frustrate self-help" (DeJong and Lifchez, 1983, p 42).

b) The home as an informal learning environment. Traditionally we accept the home as the one place where individuals have control over their lives and actions. It is a "castle," a "safe haven" from the insults of the outside world, it is a place where the individual is supposed to be able to relax, and where he or she may experiment and learn how to become a member of society.

The home provides children with their first experience of a social organization. It is the arena where they learn their place in society and the role they should follow. During infancy and early childhood the amount of learning that children do at home has been recognized. This knowledge has been capitalized on for children at risk by providing early intervention programs. These programs work with the parent and child and alert parents to methods of stimulating their children to enhance their development in the home. The home as a learning environment appears to be disregarded once the child enters public school. It is as if from that point onwards the only worthwhile learning occurs outside the home. It is instructive to review how educators have had to consider the physical environment with regard to learning for children with special needs.

The requirement to provide children no matter what their disabilities with education and training was recognized through the passage of the 1970 Education of the Handicapped Act (PL 91-23), Chapter 766 of the General Laws of Massachusetts in 1972[8], and the 1975 Education for All Handicapped Children Act (PL 94-142) which require that children with disabilities be provided with an education according to their capacity.

Massachusetts with its tradition of good education, and innovative special education for people with disabilities, endeavoured to meet the educational needs of the newly recognized population. The link between environment and education was legitimized as being necessary and vital to the child's performance. Children aged 3-21 years old who require specially designed education are entitled to a free education with materials, equipment and direct or indirect services according to the needs of the individual child in the least restrictive environment. Special educators in this state are now tested during their accreditation examinations on their understanding of how to adapt environments to support the learning requirements of their pupils.

Where children lack opportunities to engage in a wide range of activities their lives are narrowed, their efforts to control their own lives are reduced and the nevironment enourages passivity, perhaps socializing the child to being more helpless than is necessary. Limitations on functioning in the home affects the childrens' ability to move in, out and around the home, to select toys and clothes. These barriers reduce children's capabilities so that children find themselves unable to undertake certain responsibilities or roles within their families. Family members living under such conditions are "tied" to the child, in that they must always be within calling distance. This affects the childrens' sense of self-esteem, perhaps their ability to learn.

Where such conditions exist, family members and others have lowered expectations of the child, and the child performs (less competently) according to these expectations. This set of interactions obviously affects the quality of family life and the child's development. If school settings have been given some recognition as enhancing or inhibiting learning, should we not rethink the potency of the home as a learning environment? For the most part the effects of this environment (beyond early childhood) are ignored.

c) Changed expectations of and by people with disabilities. This study urges that life-cycle issues have particular significance for the handicapped population. This population's needs change considerably during the life span. Planning must reflect this. The issue being, that only dealing with the present or for the near future will predicate one type of behavior, whereas thinking of a longer time period will raise new issues and therefore influence current actions. For example, many families in the general population will purchase a home in a certain school district, knowing that the child will obtain a better education, and thus in time have greater options in life. This represents a form of long range planning. When should we think about planning for the handicapped child's future? What should parents and professionals be considering?

Perhaps the youngster may have the desire to live a life independently of the family. In such instances the better prepared he or she is, the easier it will be to make the transition. The child may outlive his or her parents. What will life then be like? How will the grown-up child manage? Where will he or she live?

We have considerable information on the problems confronting families raising children from birth to three years with severe medical problems from early intervention programs, but have relatively little information about families with pre-teens and teenagers who have disabilities. Identifying critical aspects of the lives of these families and the key factors which affect their lives will provide us with information on the needs not only of families raising a child with Spina Bifida, but of families trying to meet the challenge of raising any child with handicapping conditions.

Adults with disabilities now have access to vocational training and work mandated under the law. These rights suggest that children must be brought up to take their place in this new society. In Massachusetts, the Massachusetts Rehabilitation Commission will provide technical and financial support to adapt a home and a vehicle for children over the age of 16, who will ultimately be capable of earning a living. The Commission tries to give advice to some families with younger children, however their mandate and therefore their budget precludes them from servicing the needs of this population. This agency has been aware of the population's need and it was supportive when other agencies decided to develop a demonstration project to deal with the issue. Its support resulted in the 1984-85 demonstration project undertaken by the Massachusetts Department of Public Health together with the Adaptive Environments Center, to adapt homes where families had a child with severe disabilities. The Department of Public Health considered that they were the first state agency in the United States to undertake such a project. They have evaluated their process and the effect that making adaptations have had, and based on their findings, will in the 1985-86 embark on adapting a few (perhaps 20) more homes.

Now it is true that there are certain resources available to parents such as tax allowances on certain aspects of adaptations under certain conditions; towns with Community Development Block Grants funding can provide funds for adapting housing; Housing and Urban Development programs assistance from time to time. While this study will point out that funding is a major concern of parents, of similar weight are other, psycho-social issues. Professionals of the medical system need to recognize environmental design issues, and validate that dealing with such issues is appropriate; families have to overcome psychological as well as pragmatic problems. The specialized housing needs when raising a child may be different from the needs of adults adapting their own homes, but specific housing needs exist and present real problems.

We need to examine how society supports these families and ascertain what gaps in health and educational systems exist. We need to ask, can we enhance the quality of life for these families? This thesis probes these questions with regard to the environmental design issues of the family living as a unit in a physical setting, the home.

This study has been organized in the following manner: The first chapter outlines the research criteria, the research approach, research methods and provides the basic environmental design questions that bounded the research. The search for the sample is discussed and the demographic characteristics of it are identified. Chapter 2 profiles one family and portrays their life experiences. This is followed by a comparison of the attributes shared by families. Chapter 3 deals with design issues. It highlights the families' efforts to remove architectural barriers, notes the design process they followed, their choices and assesses the <u>effects</u> of the architectural adaptations on family life. The symbolic meaning attributed to adapting the home is considered in Chapter 4. Here parents were asked <u>why</u> they introduced the adaptations when they did, rather than at an earlier time. The link is made between parents' desires to appear normal, and for their homes to reflect such a status. This chapter suggests that it was in part these desires that inhibited families' actions. Chapter 5 reviews the findings of the study and makes recommendations with regard to policy at the State level, and possible small scale interventions that may be introduced through the efforts of individual organizations or coalitions between public, private and non-profit institutions and organizations.

Notes

1 Helen and Joseph Featherstone in 1978/9 both were teaching at the Harvard Graduate School of Education. Helen Featherstone subsequently wrote A Difference In the Family which discusses the lives of families raising a child with a difference. She wrote from the personal experience, that of having a multiply handicapped child and from parents who had written of their lives and from the shared information gained from parents in peer support groups.

2 David J. Rothman, The Discovery of the Asylum: Social Order and Disorder in the New Republic found that architects became superintendants of the first asylums, for the order it was supposed they could bring order and thus sanity to the sick, through the architectural design.

3 Telephone interview with Larry Wheeler, Director of the Office for Human Rights, the Massachusetts Department of Mental Health, June 1984.

4 L. Frieden (1980) "Independent Living Models," Rehabilitation Literature, Vol7-8 Jul.-Aug. pp. 169-173, defined the ILM as a non-residents, community based, nonprofit program which is controlled by disabled consumers and is established to increase personal self-determination and reduce dependence on others. In 1978 he surveyed 450 programs which claimed to be IL services, of these 35 were community based, but only 12 met the criteria cited in his definition.

5 In an attempt to have a complete and reliable data collection system, to facilitate planning for future health services, in 1979/80 the antiquated legislation of reporting children's health problems, in effect since the 1930's was revised, and the High Risk Infant Identification program, a system unique to Massachusetts instituted. The Department of Public Health was responsible for this restructuring, which took some time. However, by 1984 a system was in place. The program establishes 12 criteria, and if a child meets any one of the 12, he or she is identified as being at risk, subsequently all hospital contacts are logged into a computer and matched with the child's birth certificate. Stephanie Anne Weiss and Arnold M. Howitt, (1985). Medicaid under Reagan. Cambridge, MA: State, Local and Intergovernmental Center. John F. Kennedy School of Government. Harvard University.

6 Spina bifida is a birth anomaly caused by the incomplete formation of the vertebrae surrounding the spinal cord, and is a leading cause of paralysis in children. The defect affects some one or two per cent per thousand births, which means that between 9,000 and 11,000 children are born each year in the United States. Its form varies, but in the more severe cases this anomaly is clearly visible at birth and requires immediate medical attention.

Spina bifida, sometimes referred to myelodysplasia affects the nerves below the opening of the spine, so legs and bladder and bowel functions are often affected. Many of these children are either born with, or develop hydrocephalus due to the seeping of the spinal fluid into the brain, this may cause some mental retardation. The implantation of a shunt drains off this fluid reducing further damage to brain cells and this operation is generally performed soon after birth, although recently experimental surgery has performed this operation in utero.

Slowly it is being revealed that these children exhibit a constellation of seemingly disparate medical problems including swallowing, eyesight, and learning disabilities.

7 Notice of adjustment of prospective rate and charge determination. Letter filed with the State Secretary on 3 October, 1983. Correspondence from John A. Daley, Executive Secretary of the Commonwealth of Massachusetts, Rate Setting Commission, 4 October, 1983.

8 Chapter 766 of the General Laws of Massachusetts. Acts and Resolves passed by the General Court of Massachusetts, 1972. John F. X. Davoren, Secretary of the Commonwealth, Wright and Potter Printing. p. 697.

Chapter 1: THE RESEARCH

> Fate has dealt a difficult hand to children and adolescents with leukemia, cystic fibrosis, diabetes and other chronic illnesses - and to their families, too. Unfortunately, our society often makes it hard for them to play their cards well. In fact, our nation sometimes hinders these children and teenagers and their families from playing the simplest of games. (Vanderbilt Institute of Public Policy Studies brochure, 1984)

As a result of dramatic advances in medical knowlege and new social attitudes, parents raising children with disabilities represent a phenomenon which was a non-issue 20 years ago. Couples now undertake a parenting role with responsibilities for the child's physical dependency which continues long past normal expectations. For example the children in these families mostly required assistance with all aspects of grooming, in getting a meal, in moving around the neighborhood.

This study sets out to understand as fully as possible the environmental design needs of six families raising a child with severe mobility problems, and if necessary to advocate possible alternatives on behalf of this population. Certainly there was a desire by the author to sensitize others to the timbre of the lives of this population group. To do this it examined the lives of families who had, or who were at the time of the interviews in the process of making architectural adaptations to their homes. To do this it seemed necessary to reconstruct from their own perspectives what decisions families made, how they made them and why they chose particular options or rejected others.

The researcher intended to describe family life as it occurred in the home, as opposed to actions within a clinic setting, and to interview families who were not seeking help to solve emotional problems. Efforts were made to view the world through the families' eyes as far as it was possible, an emic perspective (Pike, 1954, 1966) and then to withdraw and analyze the situation objectively, an etic perspective.

Research Perspectives

The case study method offers an intensive examination of a small sample, an attempt was made to understand the extent of the problem. It was hoped that broad reading, discussions with a wider group of people, and teaching to some extent overcomes the limitations of the sample and allows a more certain understanding of the applicability of the findings.

It should be pointed out that it was difficult to establish how many children have severe disabilities. Studies were usually not comparable. They often focussed on different disabilities, ages and severities. It was apparent, however, based on the most conservative estimates that more than a million children with severe disabilities are to be found in this country.

After it became apparent that there was a sizeable population, an effort was made to find out, in what ways their housing needs had been supported. Again this was difficult. A study undertaken in England that focussed on the social needs of children with disabilities, determined that suitable housing accommodation was the outstanding problem for 50 physically handicapped children in London. The author recommended that a special housing priority be established "to provide suitable accommodation for all severely handicapped children and their families" (McMichael, 1971, p. 141).

In America recent research reviewed 28 studies which set out to ascertain housing needs for people with disabilities. Here it was found that only two provided some indication of the need of children (Agosta, J. M., Allard, M. A., Bradley, V. J., Rugg, A., Ashbaugh, J., Mace, R., and Long, M., 1984). In Massachusetts it was found that there were approximately 3,352 children between 0-18 years in need housing adaptations (Dunn, 1984). When, in 1984, the Massachusetts Department of Public Health, together with the Adaptive Environments Center undertook a demonstration project (The Adaptive Homes Project) to remove architectural barriers in homes of children with disabilities. Their funds permitted them to work with 27 families, but the director of the Adaptive Home Project at the DPH indicated that they probably had more than 900 families who needed such assistance.[1] The Department of Public Health families have incomes below a specified level.

It seems safe to state that, for this population, environmental design issues concerning the home, either go unrecognized, or when noted, are ignored. "Adapting the home" as an issue has not been shouldered as the responsiblity of any one individual or group from among the many professionals with whom families interact.

Evaluations conducted before and after the adaptations by the Adaptive Home Project suggest that homes with architectural barriers, negatively impact the developing child and his or her family. Parents may develop severe, chronic medical problems and are more likely to suffer from "burn-out," and children will seem to be less capable of gaining independence or a positive sense of self. These effects can limit their options for the future.

Apart from the current needs of these children, planning for long term care has only recently begun to be defined. Where it has, it raises special concerns which include: the characteristics of the population; viable settings for services; the degree of sensitivity to changes in medical technology; and the form of appropriate responses (Callahan et al, 1981).

The social, psychological, economic, medical, and architectural requirements of the home for this population represent a challenge, a gauntlet which demands some adequate type of response. As a society we are ignorant about the lives of such families, and more especially of families when the child is over six years of age.

> What is needed ... is the elaboration of a kind of taxonomy in which typical family "solutions" to the problems posed by a seriously handicapped child are traced out. Ultimately, we would like to see this descriptive framework supplemented with more detailed models of family structure as well. However, long before this is possible, simpler naturalistic studies that might be of interest should be carried out ... where one looks, basic descriptive work is lacking. (Gliedman & Roth, 1980, p 6.)

All in all, evidence points to the lack of immediate and long-term care supports for these families. Parents and professionals have no safe, wise, well tested guidelines for nurturing a child with severe problems to adulthood. They lack information, economic supports and models of adults with disabilities who are managing "ordinary" lives (Featherstone, 1980), (as opposed to the "super-crip").

Research Approach

With so little knowledge available, it was necessary to examine a few families' lives in some depth in order to discern the issues. This exploratory research utilized the case study method, and through it generated hypotheses which would allow questions to be posed to a larger sample in future research. When little is known about a topic, a deductive research approach which allows the data to generate theory is likely to provide insights more useful than imposing theories ahead of time (Glazer & Strauss, 1967). Such an approach allows previously unconsidered ideas to be raised and explored. This adds to the richness of the data and to the findings.

The field study viewed family life in the home as opposed to a clinic setting, and to interview families who did not feel fragile or seek help for emotional problems. Few studies exist on families rearing children with disabilities who are coping well (Bott, 1971). Research which requires more in-depth interaction with people raises certain problems between the researcher and the subjects (Bott, 1971; Liebow, 1967; Rowles, 1978). Concerns in this research were, that asking individuals to recall earlier painful events would not require too much effort, that requests for assistance be handled well, and that confidentiality of family members both inter-family and intra-family be maintained (refer to the appendix). Efforts were made to view the world through the families' eyes, an emic perspective and then to withdraw and analyze the situation objectively, an etic perspective (Pike, 1954, 1966).

Research Disciplines

In any study, the lens that is used to view the phenomena immediately determines what information gets included or cast aside. Three major fields of discipline provided frameworks to consider the data. First was environmental psychology, the environment or environmental design, encompasses the physical setting as well as the social order established within it and the culture and geographical influences that provide the enveloping context. The conviction being that people interact with the physical setting and that while physical settings can enhance or inhibit actions, they are not deterministic. For people with disabilities the press of the environment is greater than for non-disabled people (Lawton & Nahemow, 1973).

A second discipline was social pyschology, particularly organizational behavior. The families were considered to be complex organizations. As such, they exhibit behaviors found in larger organizations. They establish a culture, they vary in their degree of openness, in their ability to interact with internal sub-systems and to manage interactions with external systems. Like any social organization, families create and evolve explicit and implict rules to support their own values and like an individual they move through stages of development. It was helpful to study the subject families in relation to these issues.

Human development provided the third discipline referred to in the study. Obviously there has to be concern with the developmental cycles of children in a study of this kind. The growth and development of other children and the parents was also considered. While the literature on child development focuses on stages of normal development which is often not applicable to children with disabilities, it provides a guide for understanding this sample.

For example, these families with children with disabilities often experience an altered developmental cycle with the developmental stages occurring in a non-traditional order. The child, for example, may be unable to accomplish toilet training before the age of three years of age or older, because he or she must learn to rely on an aid. On the other hand, the child may learn psychological coping strategies at an earlier age than children without such disabilities.

Research Questions

An important aspect of the research concerned the adaptations parents chose. It was the installed architectural adaptations that were always taken as the starting point for the research. The basic questions which bounded the enquiry were: What were the families' choices and why? What effect did the architectural adaptations have on their lives? What event(s) triggered families to embark upon the design project? What type of processes did families establish? The questions around which the data gathering hinged were:

1) What did parents choose to adapt?

Did families install only the most obvious adaptations such as ramps to enable the child to get in and out of the house, or up and down within the house? Do parents make adaptations to enhance a child's ability to do things, or to make life easier for themselves? To what extent do parents design to support behavioral goals? Are design solutions based solely on utilitarian grounds? What kinds of design solutions are seen as preferable and why? Are solutions chosen so that the environment remains "as normal as possible" or formulated in some other way? What barriers did they not tackle and why? What was the effect of not removing all the barriers they had identified?

2) What effect did the adaptations have on the life of the family?

How does the child view the adaptations? To what extent have adaptations enhanced the independence of the child? In what way did the adaptations change the adults' lives or meet the goals of the family? Have the adaptations provided any unexpected benefits?

3) What event triggered parents' decisions to adapt their homes?

Did parents realise they could adapt their homes as a result of acquiring knowledge slowly, or was there some crisis? Why had they refrained from acting earlier? Were there psychological as well as pragmatic reasons that they refrained from making the adaptations earlier? Can we predict when architectural adaptations are likely to be most beneficial?

4) What strategies did parents use to adapt their homes?

This issue of "how" relates both to the generating an acceptable design, as well as installing the design. Did families develop a series of possible options? What issues did they consider in order to produce their installed adaptation? With whom in the family were ideas discussed? With what effect? Who in the family made decisions? How did the family allocate it's resources? How did families finance the project? What role if any did a professional designer have? How helpful was the professional designer perceived to be? Was the design constructed to their satisfaction?

5) What supports do families require, how should these supports be offered?

When should supports be considered essential? What did the families perceive as being necessary? What would they do if they had to start over again? What kinds of professionals should provide information on designing adaptations?

Research Methods

Data gathering. No one method would produce the information being sought in this study, triangulating research techniques, however, helped to reduce the bias inherent in any one method and made it possible to tap this qualitative information, even to get at information parents and family members may have been unaware of themselves.

To elicit information about the above questions, efforts were made to document the opinions of the parents and of the children with spina bifida and in some instances siblings. Techniques including questionnaires, unstructured interviews, keeping field notes, photography, draw-a-house test, and a review of design documents when they were available.

Questionnaires. Release forms for information and consent forms from Massachusett Institute of Technology's Committee on the experimentation of human subjects were completed. Questionnaires were used to elicit demographic information (refer to the appendix A).

Focussed interviews. Ten to fifteen hours of taped interviews were held with each family and then transcribed. The mother as the primary care-giver was the major informant but interviews were undertaken with the fathers, with the child with spina bifida and occasionally with siblings. Although the first interview was held whenever possible with parents and child being present, in general the interviews were held privately on a one to one basis. Each of the meetings concentrated on a major topic area, and open-ended questions allowed individuals to respond freely. When the responses led to an interesting, pertinent avenue of enquiry, it was either pursued at the time, or reintroduced at a later meeting.

It took about 18 months for the whole process to be completed with any one family, yet informal contact was maintained with families as the researcher met them at meetings of the Massachusetts Spina Bifida Association meetings.

Field notes. Throughout the research, process field notes were kept. Observations, thoughts about what had been retold, personal reactions to situations and information were written down. Field notes were helpful, for rather than feeling uncomfortable with an issue, it became possible to articulate concerns, and then review them more logically. When writing-up the research, the field notes helped to recall events more accurately.

Photography. Parents and children were furnished with Polaroid camera and film to take photographs in response to a booklet of questions about adaptations and use of the house, which asked for example, which adaptation has been most helpful? Questions were different for children and adults. Taking photographs seemed to involve people immediately with the project. People found it to be fun and so that they felt they were active rather than passive in the research process. This method allowed the researcher to understand visually what people were trying to indicate. (See appendix B for these questionnaires.)

Draw-a-house test. This exercise grew out of the tradition of drawing representations (Horwitz, 1982; Ladd, 1977; Lynch, 1954; Lynch & Rivkin, 1959) to explain the personal imageries individuals create. These are difficult to describe verbally. Mothers and children were asked to draw their vision of an "ideal home." This they did, but some went on to draw other images, including "home" and "best home for us now." The act of drawing seemed to encourage people to fantasize and reminisce with greater ease, perhaps this is because it requires the information stored in the opposite hemisphere of the brain from intellectual reasoning.

Review of the design documents. Where families had plans, they were reviewed together by the researcher and parents. From the plans it was possible to discuss how design decisions were made. In some instances plans were drawn one way, but later decisions meant that the adaptations were installed differently. Parents had often forgotten these earlier decisions until they looked over the plans.

Additional data gathering. The research sought information from parents regarding their own upbringing, and asked them to compare it with their child rearing practices as parents. The issue being how did they manage to rear a child when they had no precedent. Parents were also asked to recount routines, in order to understand how they had spent that day and the previous day, in an attempt to understand how much time they had to allocate to caring for their child with special needs.

Because the researcher joined the Massachusetts Spina Bifida Association, it became possible (a) to note parents of the study in the presence of others, and the kinds of information they shared during the meetings; (b) to listen to the topics of the meetings which indicated the major concerns of members; and (c) to take advantage of the opportunities to learn of the latest developments for this population which the membership provided.

In addition, professionals in the medical system were interviewed (see Appendix A-d); and the researcher consulted with family therapists to help sift personal feelings and the possible transference of these feelings to the research situation.

Data analysis. The transcribed interviews were coded. Codes were developed by noting on the interview transcriptions what seemed to emerge as an issue. When issues occurred in at least two families, they became code topics. As a new topic emerged within a family later in the process, this was added. The list of codes (refer to appendix C) were eventually collapsed if one heading had little and could be subsumed under another.

The Sample

Six families who had a child between the ages of 6-14 participated. Each family had made architectural adaptations to their homes because their children either used a wheelchair or crutches. Each child in this study was born with Spina Bifida Myelomeningocele or Spina Bifida Cystica, the severest form of spina bifida. An attempt was made to have children with intelligence as judged by the parents to be within the normal range.[3] All the families lived in Massachusetts and the parents either were or are active board members of the Massachusetts Spina Bifida Associations. No effort was made to control for education or income.

The first two families were contacted by the executive director of the the Massachusetts Spina Bifida Association, later families were introduced by people who participated in the study. Two families who were contacted declined to participate, one because it was undergoing several important changes in the family's lives, and the other, because it had no desire to be part of an "experiment."

Spina bifida was chosen for several reasons. This is one of the commonest of childhood birth disabilities and is clearly visible at birth. As far as the research project was conerned it was advisable to control the attributes of the sample by having the families combating similar medical issues. One hypothesis was that knowing the severity of the medical problems would require medical professionals and parents to plan for all aspects of the child's rehabilitation, including the home environment. This hypothesis was not upheld.

Table I displays the demographic comparisons of the sample. All the families were income producing. Incomes from $17,000-21,999 to $30,000+

Table I: DEMOGRAPHIC CHARACTERISTICS

	Smith	Politi	Simmonds	Moore	Delano	Donaldson
Age						
Mother	51	30	39	43	30	39
Father	58	39	42	41	39	47
Child	f. 14	f. 11	m. 11	f. 14	m. 7	f. 6
Other Children	1 child died when infant m. 22 m. 24 f. 25 f. 27 m. 29	m. 13 m. 16	m. 14	m. 13	--	m. 3 (adopted)
Years of Schooling						
Mother	12	12	14	14**	13 1/2	18
Father	7	12	14	14*	16	16
Occupation						
Mother	homemaker/home products rep.	homemaker	homemaker x-ray tech.	homemaker teacher	homemaker/home products rep.	homemaker
Father	superintendent - bldg. & grounds	engineer	engineer	mgr/computer marketing	engineer	sales rep.
Income	Current: 6-12,499; Formerly: 17-21,999	30,000+	17-21,999	30,000+	30,000	not provided
Years of Marriage when SB Child was Born	17	7	4	2	1	3
Position of SB Child in Family when Born	7/7	3/3	2/2	1/2	1/1	1/2

* = 15 credits ** = 30 credits

were reported at the time that adaptations were being made (from 1981-1984). Although the Donaldsons, declined to disclose their income, it can be estimated that theirs was probably at the upper level. Fathers were generally working as professionals or semi-professionals and while they may not all have had a college education, most had taken courses related to their work over the years.

Apart from the rigors of homemaking and child rearing, half the mothers worked for pay. One mother worked two shifts per week outside the house; three others became involved in paid work that they did at home (editing and writing, selling products).

Families came from contrasting cultural origins, and since cultures differ in their attitudes towards the meaning of illness and the sick role, we might expect that a family's response to the disability will reflect their cultures' values. For example parents with a Mediterranean background spoke frequently about the child being a precious gift, giving infinitely more pleasure than the effort they gave in care. All the families were Christian, and three were Catholic, two couples described themselves as regular church-goers. Most parents made statements relating to God and a sense of an overall master plan of the universe.

Formal data gathering with families took place between July 1981 to July 1984. Two families were contacted during the first year and interviews continued with them through December 1982 and February 1983 respectively. The first interview with the third family commenced in January 1982 and continued for 18 months. The fourth family was admitted to the sample in December of that year and was completed one year later and the last families were started in the Spring of 1983 and completed the following year.

In half the cases, the birth position of the child with spina bifida was that of first born; in the other three instances, the child was last born. In one family the parents adopted their second child because the risk of bearing a second child with spina bifida had increased. While parents of all later-born children tend to be more relaxed and confident of their skills at managing an infant and child, they found that being experienced parents in no way prepared them for parenting a child with disabilities. It was a totally different experience. They had to acquire new skills and a whole realm of quite different knowledge.

The findings of such a study provide us with new perspectives on the lives of the families and inevitably leads to the larger policy issues of appropriate services, for the immediate and long term care of this population. Policy has implications for such children and their families to enable them to cope throughout their lives.

Notes

1 Telephone interview with S. Lezberg, Program specialist in Medical care for the Clinic Unit and Coordinator of the Adaptive Housing Project at Services for Handicapped Children, Family Health Services, the Department of Public Health, February, 1985.

2 At the outset of the study, the intention had been to choose families with children between the ages of 8-11 years old, a stage in life recognized as latency. Because it was not possible to find a sufficient number of eligible families, the age range of the children was broadened to 6-14 years. Increasing the age range meant that the children were dealing with very different life experiences -- according to normal child development theories -- encompassing middle childhood and adolescence. Some people suggest that it is erroneous to utilize current stages of child development for children with severe disabilities, suggesting instead that they develop healthily according to a timetable of their own (Gliedman and Roth, 1980). The children at the youngest age were entering public school kindergarten where socializing is considered the most important aspect of learning and a prerequisite for formal classroom learning in following years. The younger age group thinks about issues and activities in concrete terms (Piaget and Inhelder, 1969). The older children have reached a stage where they can consider issues on an abstract level and link cause and effect more logically. They also understand the difference between fact and fantasy.

3 The intention had been to locate children whose parents considered they had intelligence that could be considered normal. The research design required that it be possible to talk with the child and to learn through photography, conversations or drawings, the child's preferences, ideas and feelings. Only one child was less able to do this due to distinctly impaired mental capacity resulting from repetitive seizures around the age of nine. The youngest child, a six-year old, was extremely shy, but able to communicate.

The youngest girl in the study was declared mildly retarded after 30 minutes of testing which required that she manipulate objects with two hands. The professional failed to take into account her need to use one hand to help her maintain her balance. Her mother, a trained health professional, considered her to be socially delayed rather than mentally retarded. Other behavior would suggest that the child was intelligent and capable of linking cause and effect. At one time she hesitated before stepping onto a shiny floor, her concern being "Perhaps it is slippery."

Recently it has been found that intelligence tests fail to measure the intelligence of people whose experiences do not pattern those of the white middle class, that they disregard the knowledge acquired by a minority groups. Perhaps a case could be made that standard tests fail to measure the intelligence of children with the types of disabilities noted in this study.

Chapter 2: THE MARATHON EVENT

It is relatively easy to empathize with a description of a single incident in the life of any one of the families, it remains impossible for non-involved individuals to comprehend the tenor of their daily routine over time. People sympathize for the moment, and then put aside such thoughts in order to continue with their lives. However for families in this study, their problems are a "forever" situation, a marathon event rather than a sprint, moreover, as ignorant as you may be about spina bifida, so were Dawn's parents when she was born.

At this juncture it seems appropriate to present a profile of one family to illustrate the quality of their life. (Profiles of the remaining five families can be found in Appendix D). Although it would have been possible to present the profile of any of the families in the study, I chose the Moores because since her family had coped with the challenges for the longest time. The members of this family were particularly articulate, and it was usual for them to analyze incidents in terms of "causes and effects" to their lives and for future actions. Since they were more conscious about how they planned they were capable of <u>sharing</u> why they undertook certain actions. Although the most clearly verbalized rationale will not reveal the subconscious reasons for taking certain actions, at some point it becomes necessary to accept the families' version as being as honest an answer as they could provide at that time.

Another consideration for choosing the Moore family was that they had relocated approximately every two years, and in order to simplify their searches for new homes, the parents developed criteria for realtors.

They differentiated between the essential attributes of the "basic" house and the adaptations they would be willing to undertake (usually by themselves) and live with for a "short" stay.

When I first met this family, it seemed that life was moving along smoothly and routinely. Yet only a few months earlier, Dawn had undergone a spinal fusion operation and a subsequent six month recuperation period in a body cast. During this time she was unable to get beyond the driveway in her rented reclining wheelchair and it took such energy to "fit" her into the car that the family felt it was not worth the effort. She therefore went out maybe three times during that whole period, it was as Sandra Moore, the mother, described "one of the most frustrating periods of our life."

Although the family probably now enjoy the highest income of all the families, they were "poor" when Dawn was born. Moreover as John, the father, pointed out,"[now] as middle income people, we never fit any financial eligibility profile, everyone (authorities) expect us to be capable of managing financially which isn't necessarily the case when rearing a child with such physical problems. If you're even $200.00 over the level, you end up having to pay for so many expenses out of your own pocket that you'd be better off having a lower income."

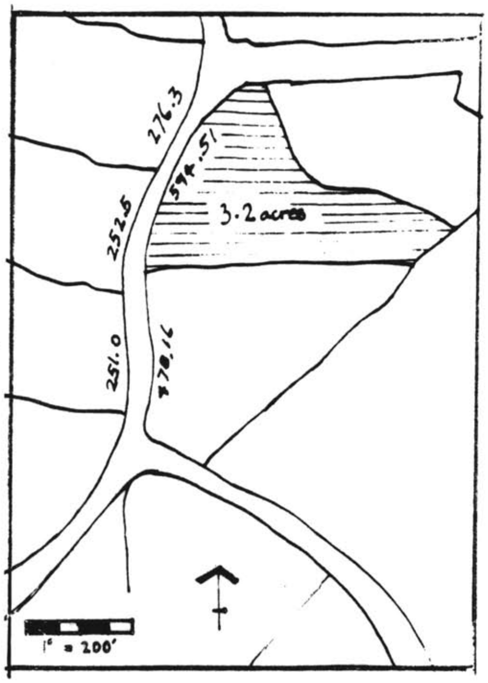
Profile of the Moore Family

Phrases which describe this family: flexibly traditional parental roles, goal oriented, articulate, conscious of emotional well-being of each family member, brisk, taking charge of their lives, reflective of experiences, independent, upwardly mobile, connected to community and society.

Father: John 41, a computer marketing manager
Mother: Sandra 43, free lance writer, editor and substitute teacher
1st child: Dawn 14, jr. high school student (spina bifida)
2nd child: Eric 13, jr. high school student

Photograph 1: View from sidewalk

Plan 1: site plan



The Moore Family: In general the family displayed a thoughtful but positive attitude towards life. John explained, "We prefer not to use the word 'disabled,' rather we consider Dawn to be 'inconvenienced' or 'physically challenged,' we all have problems to overcome, and her's are specific and visible." He and his wife had always encouraged Dawn with "Life should not be less fulfilling because you have to live in a wheelchair. People with disabilities can do anything they want to do -- scuba diving, a career, anything. If Dawn complains, we respond 'You've got four legs (wheels) instead of two. You can't complain about it; it's the way things are. Look how good this is, and look at that ... Life may be less convenient and there's always something you can fix somewhere."

Dawn's parents describe her as "highly intelligent, well motivated and competitive." John indicates, "She suffers from the 'first child syndrome,' and as parents, we have high expectations. At the moment she is interested in studying some sort of math or science, perhaps medicine. I have no sense what sort of a chance she'll have at getting into a good medical school, and I know that getting into medical school is highly competitive, but I am not discouraging her in any way. We tell her, if she does want to study medicine she's going to have to work twice as hard as anyone else in the class if she's going to make it. If she's prepared to do that all well and good." Dawn explained "I used to like math, but lately I've become interested in radio and sign language, and I plan to take courses in these subjects."

John volunteered, "Eventually, most of us (parents) find out that more physical therapy will make little difference, and once you swallow your pride and recognize what the debilitations really are, then you can redirect your energies into helping the person achieve their (his or her) potential, and I think that's what we've done since she was probably five years old." As parents they had always been counseled by professionals to "Treat your child as normally as possible." They had tried to do this in as fair a way as possible. John admits, "I'm sure that every parent treats their inconvenienced child differently from their other children.

Their second child Eric a quiet, even shy, sports loving boy who similar to most boys of his age spends as much time as possible with his friends. Sandra, conscious of the value of structuring one's time well, is trying to teach him this. It is a skill that he does not come by naturally. Eric does not take kindly to his mother's questioning as to where he is going, with whom and when he'll return. He has no wish to be treated as a "baby."

The parents do not allow the children to be out alone in the evenings feeling "there are enough daylight hours in which to have fun." There is the usual sibling rivalry between Eric and Dawn, but being so close in age, they have done most things in tandem. They attend the same school, go away to the same summer camp and do their homework on the kitchen table together. On the weekends during the school year their sports interests take them in different directions.

Both children are responsible for chores, but as John pointed out the chores Dawn had to do were of necessity different from her brother's, but she had to be responsible for those she was capable of accomplishing. "Some parents of children Dawn's age do everything for them; one wonders when they'll (the parents) let go. It's far easier (for the child) to learn to do things gradually." They (the children) must take care of their own room, make their beds, and do a certain amount of vacuuming. Eric helps John in the yard, clearing brush, cutting, splitting and stacking logs and loads the dishwasher; Dawn takes care of the window boxes, feeds the dogs, hoses down the cars and clears the table.

Living in a semi-rural setting means the parents have to carpool their children to activities (as are all other parents). This places Dawn on a more equal footing with her peers, for she is equally dependent on an adult in order to get to a specific location. In neighborhoods where teenagers can negotiate the locale, her mobility impairment would be further emphasized.

When searching for a metaphor to describe themselves, more than one member of the family used the word "team." "Team" because it meant belonging to a group with clear goals where each (family) member must pull his or her weight. The metaphor gains in meaning when one realizes that the family actively participates in sports. John coaches the Easter Seal swimming and basketball programs in which Dawn participates from December to May. During these months Sandra spends time with Eric, carpooling him, when necessary, to his sports events which change according to the season. Between March and September, John helps coach Eric's basketball team, and Sandra spends time with Dawn.

Sandra comments "Saturdays are a rat race. The children have their team sports so we're carpooling, coaching, whatever. Dawn may go to a mall with a friend after swimming. Eric might go off with his friends or decide to go to a second game, but may require a ride home between games."

"Sunday mornings we get up late and "attend" the television church service. We're given up going to church because we won't lift Dawn up flights of steps. We've done about all the (unnecessary) lifting we're willing to do. We try to take it easy on Sundays -- we try to tone down the 'crazies' of Saturdays. We may take the dogs for a walk, do some household chores, take life easy. There's so much work to be done, we sometimes look around and wonder where the weekend went to." "John and I might go to a movie on the weekend, nothing fancy. Maybe two or three times a year we go into Boston to see a show. That's a disgrace."

As a family, they play board games, cheer the Boston Celtics, "attend" television church services, and enjoy an active social life. Life changes in the summer "... Our house becomes a resort hotel with people coming to stay over every few days." The swimming pool became a neighborhood attraction, drawing friends and relatives of all ages, like bees to a hive, so that even though the pool was installed as a therapeutic aid for Dawn and was therefore a partially deductible as a medical expense, it has become an attractive amenity for the whole family.

The stance John and Sandra take when adapting their homes is that Dawn's bedroom and bathroom should be as convenient and pleasant for her to use as possible, elsewhere the house should be convenient, but adaptations in these locations should not impair the comfort of other family members (all of whom are nearly six feet tall).

Consciously maintaining the emotional well-being of family members was characteristic of these parents. One example would be that they will remain in this locale until the children complete High School because this last move (two years ago) was unsettling for their son Eric. It had come at the "wrong" time for him, and required considerable effort by his parents to help him adjust to the wrench of leaving friends.

Sandra, a substitute teacher at the high school, had decided with John that the following year she would return to full time work. She had taken the initiative to develop a proposal for a unique school program which would create a position for herself. In order for her to return to a full time job, the couple were renegotiating how they were going to manage the home and family.

The family appears so stable and well balanced that one might have cause to believe that this came about naturally, perhaps without effort. This was not the case. To achieve a smooth running family required the input of time, thought and energy as does any complex, well organized system.

Their daughter's disability came as a complete shock to John and Sandra. They had never heard of Spina Bifida "Initially, we were led down a very bleak path. The neuro-surgeon said Dawn would not live, and if she did, it would be better if she died because she would be a vegetable. 'This is not something you really want to get yourselves involved with at all.'"

Against all expert advice, the Moores decided to bring their baby home. Neither set of grandparents were particularly supportive, they had no wish to watch <u>their</u> child shoulder such a burden, they urged the young couple to leave the infant in the hospital. Never did they enquire how the couple was managing, nor did they offer to ease their financial distress. Sandra and John found this behavior hurtful and they have never forgotten it. Despite the poor initial response from grandparents, by the first Christmas they rallied around, and over time they and other family members have been supportive and provided babysitting, something that is particulary important when Sandra had to house hunt.

After Dawn's birth, the young couple were harried by the enormous medical expenses. John, just out of school, had started a new job just one week before Dawn's birth. The expenses incurred by her medical problems and a subsequent grave illness of Sandra were not covered by insurance. Five years later the couple were still paying off these medical debts. Memories of this experience continue to influence John; he now negotiates aspects of medical insurance when interviewing for any new job.

John and Sandra also pointed to incurred hidden expenses which are not easily identified or remembered, such as "When buying a car, we always check the car trunk first -- will it take the wheelchair? We buy a car with leather seats, not fabric, for it is easier for Dawn to slide over. Because of her problems with balance, she needs an arm rest and does better with a contoured seat than a bench seat. When she was in the bodycast, she had to use a reclining wheelchair. Being in that awkward position, she had difficulty in manoevering the chair, so the wallpaper got damaged. It's those sorts of things that cost money, but you don't necessarily think about them as obvious expenses."

When, to every medical professional's surprise, Dawn (the infant) thrived -- even showing precocious intelligence -- the routine of their lives became dictated by physical therapy. The clinic Dawn attended was guided by a theory that even a child with Dawn's disability would be capable of walking given much therapy and assistive devices. "For the next three years," recalled Sandra "five mornings a week from 9-12, Eric and I passed the time in hospital waiting rooms." The regimen was discontinued only after an examination by a Canadian physician who lifted her leg in the air. Letting it drop with a thud, he asked, "What makes you think this child is going to walk? Don't you realise she's walking on her hands?" John continued, "Our response was 'Of course she's going to walk, everyone has told us this is what will be.' We were stunned by his prognosis, but once we absorbed what it meant, we could plan for a new set of circumstances. We knew that our daughter would be using a wheelchair. We knew that visions of her walking in any fashion were unrealistic."

Interactions with medical professionals and systems around the country has taught Sandra "...physicians try to put you down and treat you as a lay person, but I push, even hound for explanations. Yes, I feel hostile towards the medical profession. You either have to be educated, or you must educate yourself, or be taken. Dr. X, the orthopedic surgeon, is someone I respect. He talks to the kids not [only] to the parents. He explains...he's honest...and he's very conservative when it comes to surgery. I sometimes think surgeons are born with a silver scalpel in their mouth. They are over-zealous in wanting to perform procedures when they are not absolutely indicated. I tell them to 'buzz off.' I would never prevent Dawn from having a beneficial medical procedure; on the other hand, I do not want her to have to undergo unnecessary procedures."

To return to the issue of the hard-won stability and integrity of the family. This status was gained by constant effort on the part of the parents who recognized the need to set aside time to plan for their family's well-being. "Initially [after Dawn was born] we didn't talk much." The parents found that each was locked in a personal world of misery, not sharing thoughts or feelings. Eventually this matter was brought to a head by one parent initiating and pressing the need that they must talk together. "We realised that if we didn't start sharing some of those feelings, we would never get to first base." Since that time they made sure that they left the house, if only for a couple of hours each week to "take the pulse" of the family. At these times they reviewed what was happening and how they should manage their lives; they made decisions concerning immediate issues and planned for the future. To help themselves and to gain some understanding of the new world (of disability) into which they had been plunged, they became founding members of a chapter of Spina Bifida Association in New Jersey.

The parents had never found a barrier-free home and had always to compromise. "You buy something which is not completely satisfactory, but has the least amount of bad things." John identified "...a place you can make the most comfortable, a house with a bedroom and full bathroom (where a wheelchair can turn) on the first floor."

They learned over time that any adaptation they installed should not jeopardize the sales appeal of the house. They found that ramps designed as an integral part of the landscape were viewed positively. But as far as kitchens were concerned, would-be buyers wanted a self-cleaning ovens and to install a side opening oven that required heavy duty cleaning would definitely reduce the "value" of the kitchen.

Their newly built home is sited in a semi-rural area where riding stables and an occasional farm dot the rolling countryside. They chose the town because while they like country living, they appreciated the cultural events to be found in Boston some 20 miles away. They approved of the town's good school system, and the quiet streets were safer for Dawn on her electric bike. Their house lot is slightly larger than their town's three acre zoning requirement, and Sandra estimated the value of their home in 1983 at approximately $300,000.

The three features that attracted them to the house were: a bedroom and full bathroom on the first floor (for Dawn); halls wide enough for the wheelchair to turn corners; and, last, the ability to ramp an exit. A detailed description of the adaptations and their effects will be discussed in a later chapter.

The family had first built a barrier-free home when Dawn was eight. It was only during this series of interviews that the parents realised their renovations had always evolved from evaluating what had or had not worked for them in previous homes, never from the premise "What would we ideally like?" When considering the kinds of physical spaces they required, this family utilized a problem-solving strategy that had successfully generated solutions when dealing with psychosocial problems arising in their lives. They established goals and identified functions. They provided the following example of a behavioral goal they used when dealing with a spatial issue: "Dawn needs to be able to make her own bed, therefore she must be able to wheel around both sides of the bed."

The parents' actions from the time Dawn was a toddler ensured that she would gain mobility and independence at each stage of her development. They bought a Krazy Kar -- a hand operated toy -- when she was a toddler, and as she grew, they bought larger versions of this type of vehicle. This vehicle enabled Dawn to keep up with other children and come or go at will. As a pre-schooler, Dawn was able to dig in the dirt or play in the sandbox from her vehicle. The parents "relaxed" their rules and allowed her to use the toy indoors. Now Dawn runs an electric battery-operated bike which gives her the ability to travel about twelve miles distance. She wants to learn to drive as soon as she is old enough and is pushing her parents, as do most teenagers, to let her get behind the wheel of a car.

Surprisingly enough, Sandra Moore marvelled at her daughter's strong desire for independence and wondered how she came by it, especially since Dawn announced to her parents when she was quite young that when she was eighteen she would live on her own. "I've applied for the position of manager of the school's basketball team, and I'm hoping to become a counselor-in-training at the summer camp that Eric and I go [to]."

"Dawn's a go-getter. She's an activist," said her mother. If she finds architectural barriers in her school, she speaks to the principal. If the changes are not made within what she considers to be a reasonable length of time, she will contact him again and ask what happened to her request. She's equally as assertive about challenging social barriers."

The parents believe that "It is important that Dawn earn her own living, drive her own car and be as independent as possible. It is our intention to ensure that she can manage without assistance before she leaves high school. We expect that Dawn will go to college -- preferably in a warm climate -- and that she will live away from home and on her own."

As to the future, John anticipated, "When the children have gone and are away into their professional lives, we'll maintain a bedroom-bath combination on the first floor, as in this house. We'll always have some comfortable provision for Dawn to come and stay. But as a father, I would not feel under the same obligation to put long handles on the faucet for it [the home] to be convenient for her."

The profile of John, Sandra, Dawn and Eric Moore begins to inform us of the considerable thought, sensitivity, planning and resources they expended in order to organize their lives and provide the best opportunities for each member of the family.

One might have expected that given the latitude of the eligibility requirements, the sample would have included a broader range of families. The similarities among families were significant for they suggest that the presence of certain characteristics will establish a set of circumstances which will allow families to adapt their homes, creating an enabling environment for the child and family. The similarities among families included:

1. Homeownership: All the parents were homeowners, not renters.

2. Intact marriages: All the parents were married at the time when the adaptations were made[1].

3. Involved Fathers: Fathers were physically and psychologically present within the families. They were involved with their children affectively and intellectually and many assisted with routine chores and even took on additional "mother's" chores. The men were instrumental in choosing, refurbishing and decorating the house and most were capable of undertaking home improvements themselves.

4. Homeostasis of the Family: Most of the families were sensitive to and planned for a balance of the physical, intellectual and emotional well-being of each family member and for the emotional balance of the family as an organization.

5. Social Life of Couple: Most parents ensured that the family had some organized social life and tried to set aside (on a regular basis) some time for themselves as a couple.

6. Kin Network: Families who had a network on whom they could call upon should the need arise; or were able to call upon the network found that this (network) provided stability, an increased sense of well-being, even freedom.

7. Planning and Management: Most families learned to identify problems and the need for change; they had to learn how to set goals, to organize a project and see it through to completion. They had developed a viable communication "system" that facilitated the manner in which they made decisions, shared power, and utilized their resources. The families were capable of creatively expanding the boundaries

of their personal resources and of utilizing community resources.

8. Personal Characteristics: All the families had high energy levels, willpower and tenacity of purpose. They had confidence in their own judgements and a willingness to solve novel problems. All the parents had, for example, changed their physicians at some time because they disagreed with a mode of treatment, disapproved of the professional's interpersonal style, or because their medical expenses would be covered more completely elsewhere. This is generally difficult for lay people to do, since medical professionals often present a paternalistic stance, and exude a confidence that they are correct, even all knowing.

It was because parents and families in this study had the attributes noted above, that they are defined as strong and successful. If, in spite of their remarkable strengths, they found it difficult to make architectural adaptations, and perceived the action to be fraught with sufficient frustration that they compared themselves as pioneers blazing new trails, it is reasonable to expect that families with fewer innate or learned skills or advantages would find the task formidable.

Notes

1 Graham Smith died the year before the interviews took place.

Chapter 3: INVENTORS, EXPLORERS, EXPERIMENTERS

> Individuals who will succeed and flourish will be masters of change: adept at reorienting their own and others' activities in untried directions to bring about higher levels of achievement. They will be able to acquire and use power to produce innovation.
> Rosabeth Moss Kanter, The Change Masters

So far I have said little about the design processes families used or the design solutions they chose. Common sense might predict that families would adapt certain features of their homes: bathrooms, steps, circulation paths and inconveniently designed rooms. Such assumptions were borne out, but they were not uniform across families. Some families introduced unexpected seemingly extravagant additions such as swimming pools. Of particular interest to this study is to understand how families managed the change process: What triggered families to embark on the changes when they did? Where did families find information? What kinds of information and practical assistance did they require?

The adaptations undertaken by families ranged from doubling the size of their house or building a new house with the assistance of professionals, to making minimal adjustments, perhaps in incremental stages as "do-it-yourselfers" or with the help of friends and relatives. One family had moved five or more times since their daughter was born and in doing so learned to acquire homes which required the minimum of change.

It was surprising to see how long parents waited before starting to adapt their homes. The reluctance of families to change the home can be explained in practical terms as well is in psycho-social terms.

The emphasis of this chapter is on the practical difficulties families encountered. Most frequently, families mentioned difficulties such as a lack of time and energy due to their child's frequent medical crises, an uncertainty about the child's future, high costs and a lack of design precedents for creating a barrier-free home for a child.

There is evidence to suggest that people will modify their behavior to prevailing conditions rather than move around non-fixed elements such as partitions or heavy pieces of furniture that might be used as room dividers (Steele, 1973) and irreversible changes, such as removing a wall, are even more difficult for people to consider. Even when individuals have physical disabilities which impede their ability to circulate through their homes, first they modify their behavior, only when doing this fails to accomplish what they want will they adapt their surroundings.

Expenditures of money and time are not the only inhibiting factors. People prefer that their lives continue in the security to be found in routines. Making architectural changes breaks into their routines and imposes additional strain on the family. While routines may be enlivened by a certain degree of pleasant or perhaps unexpected stimulation, the range of what is acceptable varies with individuals. For some families making architectural adaptations introduces an unwanted degree of stimulation and ambiguity, for they have no assurance of the outcome, nor do they know the process to do it.

Groups of all sizes endeavour to remain as stable as possible; nevertheless, there comes a time when they must introduce changes. Whether the group is a family or a more formal organization, it becomes aware that it needs to make a change when pressures builds either from within the group or from the external environment (Beckhard and Harris, 1977). When first confronted with the need to change, an organization's automatic response is

> "to hold hard to the known; to deal with the symptoms while hoping that nothing more serious has changed. (Resistance to change is a basic property of all systems and essential to their survival.)" (Roeber, p.ix, 1973).

The degree to which a family plans for change or is forced to change depends upon their planning style. Organizations have been described as predominantly goal-oriented planners or directional planners (McCaskey, 1974). Families, it has been noted, probably use a mixture of these two modes, for each has advantages and drawbacks (Gross et al, 1980). All in all, it is easier to be goal-oriented when the outcome is clearly delineated and the paths to the goal are familiar. Arranging a Christmas party would perhaps be an example.

Where the final goal is hazy and the route novel, then the group or individual is probably better off following the directional route. This allows for the testing out of ideas as the process is underway and of ascertaining new possibilities as they arise. In terms of this population, "to become more independent" may be considered direction-oriented. When achieving this generalized ideal includes mini-goals and a reasonably clear means of achieving the final outcome, then this can be considered goal-oriented. These approaches relate to families' styles of managing.

The management style of the parents, whether they are dealing with routines or pressured circumstances is no doubt influenced by a number of variables: social/economic status, education, life experience and personal characteristics. Accumulated experiences establish the parents' decision-making capabilities and the degree to which they feel they can control or have the right to control aspects of their lives. It appears that the processes they used with regard to adapting the home followed the planning style with which they dealt with every day life. This uggests a typology of families' planning styles along a continuum of proactive - reactive - fatalist. This typology will be detailed later.

Lest there be some pejorative or laudatory value attributed to the planning typologies, it should be pointed out that proactive planners do not necessarily represent superlative models nor should fatalists be viewed negatively. Indeed, the proactive planners on one extreme of the continuum might overplan and use the practical activity as a buffer insulating them from less pleasant emotional issues. Fatalists, on the other end, may have a religious belief that life is part of a pre-ordained scheme and therefore in the "hands of a higher power," derive strength from this and work to become worthy of the challenges they are offered. Alternatively, they may feel that they enjoy the daily events more completely because they are not taken up in a flurry of activity for some future situation, which, as they see it, may never come to pass.

Either attitude may be viewed as acceptable so long as it does not stultify growth and development. Most families in this study moved along the continuum of planning styles. Presumably most parents can move along it in either direction when given the stimulus and support and information. People are capable of modifying their behavior, especially if the outcome will be sufficiently rewarding. It is therefore probable that people could adopt alternate planning styles.

Proactive families tended to be goal-oriented. This group of planners exhibited certain qualities: a) they had gained an understanding of how to set goals and manage situations in larger organizations outside their homes, b) they were able to assemble a body of relevant knowledge pertinent to the change situation, c) they could plan projects in a logical sequence, they projected beyond the immediate situation and considered the future.

These families were more capable of identifying an action their child should undertake and then to consider how the setting could support it. They wanted to take control of their lives. They were ambitious. They intended to achieve. Such parents transferred skills They had gained in their work environments, where they had been required to set goals and to establish the means by which such goals could be attained. When thinking about their homes they did not necessarily enumerate goals and objectives on paper (although in some instances they did do this), but they were "future-oriented" and were more likely to consider the welfare of all the individuals in the family. They understood a basic need of the child was to acquire increasing independence, and therefore set out to ensure that their child would acquire distinctive skills. In taking action, they experienced the reward of feeling increased competence as they generated options for the family. Their efforts, as they saw it, enhanced the quality of family life and provided their children with opportunities of reaching their potential.

Reactive planners thought more in directional terms and in generalities, "We want our child to become more independent." These directional terms came to mean getting in and out of the house and moving through it. They did not identify distinct mini-goals to help their child attain proficiencies. Reactive planners knew that they were going to have to make changes but held action at bay, and maintained the status quo for as long as possible. Parents recognized that once they started to make changes they would have to reorganize their resources to resolve difficult problems. They realized that they would to deal with considerable disorganization and extra work caused by construction. Reactive families wanted to relax and "take a breather" on the comfortable, familiar plateau they had reached (Vaillant, 1977).

These families indicated that they had discussed ideas for a long time, so when they finally "took the plunge" they had a fair sense of what they were capable of undertaking. Their children were of school age and were facing increasingly complex challenges in life, and as parents they wanted their children to learn, to develop and become more appropriately independent. They did not identify, functions such as making a sandwich; washing clothes; clearing the table; gardening.

This group of planners made adaptations in response to situations. They a) considered making the adaptation for some time, but refrained to do so for various reasons, b) had less opportunity in their work life to function as managers and c) had greater need than proactive planners to have visible examples as models.

The fatalistic family took life as it came. What would be, would be. The family had a) a laissez-faire attitude to education, jobs, and marriage, and b) no clear ambition goals for their child and therefore had less incentive to make her more independent.

The Smiths had never established ambitious goals for their older children and considered "that they have turned out all right." With Dianne they did not clearly enunciate the idea that Dianne should become fully independent. At birth Graham had said "It's just as well she's a girl," explaining later, that "Girls did not have to go out and earn a living or take on the responsibilities required of a boy."

Until Graham Smith was galvanized into making changes, by the knowledge of his ill health and later of his impending death, he carried his fully grown daughter upstairs to the bathroom three times a week. That Dianne wanted to bathe more frequently was an issue, but not of sufficient weight that they change the house.

It appears that families can change their planning attitudes from fatalist to proactive, and move in either direction along the continuum. The Moores were a couple who started off as being reactive planners, and were "compelled" to establish improved communication between themselves soon after their daughter was born. Later they were "forced" into making adaptations by ill health. Over the years, because they relocated around the country, they gained invaluable experiences. They learned how to deal with different people, medical and school systems and homes, and in so doing they accumulated an unusual amount of "savvy." This contrasts with families who, having a child with severe medical problems tend to remain in the region, once they had found a good medical center. Once attached to reliable physicians, supportive medical and educational systems, families cringe when they visualise the efforts they would have to expend again should they relocate. Once they have adapted a home, they are even more reluctant to go through the process all over again.

The Moores recycled their learning and applied it to new places and situations. They gained an ability to plan by linking a desired activity with an architectural solution. "It is important for Dawn to be able to get out of the house in an emergency, therefore we must provide emergency exits from the rooms she most frequently uses, particularly the bedroom." Over time they _learned_ to become proactive planners, (in table II they are listed as reactive for that was their situation when they adapted their first home). The Smiths had to become reactive planners to make changes.

The Design Cycle

It is now necessary to return to the issue of changing the home, and to the concept that in general, people tend to procrastinate in altering the physical setting. One life event for which many cultures plan environmental changes occur when a woman expects and bears a child. With the arrival of a child, parents change their routines and make a welcoming physical space available for the baby and his or her needs.

The popular literature for new parents, such as Better Homes and Gardens Baby Book, the American Parent Magazine and others, base their advice on research proving that children mature physically, psychologically and socially in predictable sequential stages. Their recommendations cover appropriate apparel, activities, routines and arrangements of the physical setting for the child as he or she develops. While some of their advice in the very early days is appropriate for families of this study, eventually these parents must devise new solutions, since popular magazines rarely include articles about people with disabilities at home.

The family raising a child with disabilities has probably introduced a greater number of environmental adaptations from the very beginning, than all other parents. Their children may have used a number of aids: parallel bars for walking practice; a parapodium for standing; braces and crutches. All aids require specific changes, perhaps a modification of behavior, or certainly a use of the physical setting.

When the time came for the parents in the sample to remove architectural barriers in their homes, they embarked on a sequence of actions which was different from their accustomed routines and outside their immediate culture's repertoire of familiar knowledge. As non-designers, parents' actions formed a sequence which encompassed five phases: 1) scoping the problem, 2) scouting for information 3) design, 4) construction, and 5) experiencing and learning from the design.

For lay designers the entire design process is (obviously) more informal when compared with that organized by professionals (Hack, 1976; Zeisel, 1979). Whether the process is formally directed by professionals or informally discovered by lay people, it tends to be an iterative one where information is recycled back and forth between phases, and considered in relation to the individual's or groups' growing body of knowledge. These phases lack firm boundaries, they blend one into the other, especially through the design phase.

During the transitional period, that is from the time the family seriously considers building adaptations to the time such changes are in place, tension mounts. Families found they had to make many choices with too little knowledge. They had to take on additional tasks. Even families using professional designers sometimes found the process to be one fraught with anxiety, causing couples to argue about the choices they had to make. The process of managing transitions in families had many elements noted when formal organizations undergo the a similar process (Beckhard and Harris, 1977).

To understand something of the process, consider the following: for some time a family feels that they ought to do something about their home, they see a ramp on a home, this reintroduces the subject; they review their readiness to undertake the project; they check their resources, if they lack the money, they look for a means of funding the project; simultaneously they try to reduce the need to spend actual money by assessing their ability to construct the design themselves. They decide that in order to complete the task they should learn certain aspects of the task. Such deliberations may cause them

Table II: TYPOLOGY OF FAMILIES AS PLANNERS, ARCHITECTURAL ADAPTATIONS, ASSISTANCE FOR PROJECT

TYPE OF PLANNER	FAMILY	CIRCUMSTANCES	CHILD'S AGE AT 1st[1] ARCHITECTURAL ADAPTATION	PROJECT	ASSISTANCE
PROACTIVE PLANNERS	Donaldson	Anticipated increased problems (mother's medical training)	5	large addition	prof designer & contractor
	Simmonds	as above	4	moved & adapted	Self-help & community resources. MSBA grant
REACTIVE PLANNERS	Moore	Parental medical problems	6	(moved) moved, adaptations	(Prof designers) & contractors & self-help
	Delano	Personal pref & Parental medical problem	9*	(built home) built home	prof designer & contractor
	Politi	Parental medical problems	10	adaptations	self-help & kin network. MSBA grant
FATALISTS	Smith	Parental medical problems	12	adaptations	self-help & kin network. 2 MSBA grants

* child uses braces and crutches

[1] First action family took, not necessarily to current house.

( ) undertaken in the past

to assess different building materials, which, in turn, may suggest an alternate design.

The larger projects, a new home for the Delanos, and the extensive addition by the Donaldsons were (as might be expected) designed by professionals. Here plans were drawn up for the design and the phases more clearly defined and the more complex the project the less flexibility there is to alter plans especially once a design has been selected.

Phase 1: Scoping the problem

When did families in the sample decide to adapt their homes? What events precipitated their decisions to make architectural adaptations?

In trying to explain why families behave in a certain manner it might be helpful to recall the families' rhythm of life and how their energies had been engaged. For approximately the first seven years of life, the family with a child with spina bifida, confronts many stressful situations. Some caused either by chronic medical problems or acute medical crises. Families had to cope with the "extraordinary" while managing the ordinary circumstances of family life (which might include rearing their other children without such disabilities). They had learned how to establish a form of family life dissimilar from relatives' and friends' child-rearing experiences. Couples had to gain knowledge about a relatively unknown birth defect and to acquire skills at interacting with health care systems. Moreover they had to face the social perceptions of disability within the community, from family members, and prejudices within themselves.

Table II displays the ages of the children when the families made their first major architectural adaptations. Among the sample, certain families (Simmonds and Donaldson - proactive planners) started to adapt the home when their children were pre-schoolers. The oldest child (Smith-fatalists) in the sample was nearly a teenager when the home was changed. Three families (Politi, Moore and Delano -reactive planners) made changes when their children were of school age.

Why did the Donaldson and Simmonds families consider the architecture of their homes when their children were so young? In discussing their situations, these mothers considered their educational and professional backgrounds in the medical field, gave them an advantage over their peers. Perhaps these parents accepted their own child's disability more readily because the mothers had met people with disabilities in their professional work. Perhaps they were able to perceive the personality of the individual that existed beyond the facade of the disability. The mothers considered that their medical training had familiarized them with medical systems, and, because they knew how physicians and other medical professionals proceeded, they were able to obtain an earlier prognosis for their child. Mothers recognized the increasing awkwardness of carrying the child up and downstairs and anticipated the increased effort that would be required in the future. All of this knowledge enabled them to adapt the home when the child was younger.

No parent, within this sample ever had a professional from the medical system enquire how they were managing at home. In two instances a physician recommended that the family install air conditioning to make the child more comfortable while she was in a body cast, and in other instances that swimming would provide therapeutic exercise. (Prescription for these items allowed part of the costs to be considered as tax deductible medical expenses.) While it may seem logical that physicians paid no attention to what happened within the home, it was surprising that professionals, especially those concerned with child development, including occupational therapists and physical therapists, or social workers concerned with family interaction would not have included an assessment of the house as an important diagnostic tool, knowing that the home affects the quality of family life and the functioning of the child.

Individual professionals may sense that this is important, but <u>they</u> state that parents are reluctant to face such issues because they immerse themselves in the medical issues.[1] On the other hand, professionals interviewed during this study admitted that they knew little about adapting the home, and did not introduce the topic to their clients. They asked me to recommend resources, including designers or funding for making architectural adaptations.

Over a three-year period, the Massachusetts Spina Bifida Association presented programs which focussed particularly on medical issues, never on barrier-free architecture or the effects of the physical environment on independence and behavior. Their library, contained some books and a bibliography on these subjects, and from time to time an article appeared in their newsletter on barrier-free design generally explaining an aspect of legislation pertaining to public buildings, or new housing legislation which could apply to installing barrier-free designs.

Although parents in this study were energetic individuals, it appears that as long as there were other strong people around to provide necessary "muscle power" they were less inclined to adapt the home. In families (Politi, Smith) where older sibling(s) assisted with the lifting, parents refrained from making adaptations for months or years. People used time and personal effort in order to cope -- "free" resources taken for granted by healthy, energetic people. Eventually it became apparent when they acquired medical problems from carrying and lifting their child, that a cost was attached to their physical efforts. When their physical strength was unavailable, they realised the necessity to generate or substitute alternate resources (Lawton and Nahemow, 1973).

Parents ruminated about ideas and possibilities over months, even years, clarifying their vision. Politis, Moores and Smiths (reactive planners) made changes only when they were compelled to because of their newly acquired medical problems (see Table II). Back and shoulder problems and hernias were the medical problems reported by parents. The Delanos who had always intended to build their own home, pointed out that Sharon's already weak back was giving her greater discomfort as her son had grown bigger. Months after Mr. Smith had his heart attack, he learned that he had terminal cancer, and knew that he had no alternative but to make changes.

Families faced serious practical constraints, not the least of which was a lack of critical information about their children. We should not, therefore, be surprised that families hesitated to embark on an (alien) undertaking. Perhaps under the circumstances a family's "non-action" represents an appropriate coping strategem, an act of self-preservation, since an individual is capable of dealing only with a predictable amount of stress at any one time to remain in good health (Holmes and Rahe, 1967). To manage a novel situation (which is what architectural adaptations represent), the family must be ready, capable, and willing to manage both the ongoing family life, and organize and manage the intended transition period (Beckhard and Harris, 1977). They must set in motion an unfamiliar set of actions in a syncopated life. The actions would for the short term create more stress in their lives.

The first stage "scoping the problem" is reached when parents recognize that a problem exists, they have some sense of its dimension and believe that they are ready to tackle the project. By this time they have recognized that approaches and information are required beyond their experience even if they do not know the degree of their "ignorance." Proactivists, being capable of envisioning possible scenarios are in a better position to predict problems and avoid them through planning.

Phase 2 Scouting

Scouting is for lay designers, what design programming is for professionals. Definitions and descriptions of design programming for professionals, by professionals exist, (Hack, 1976; Palmer, 1981; Pena 1969; Zeisel, 1979) but little has been written about process lay designers use. During this phase, people establish goals, set priorities and identify resources. Design professionals will write a document (the design program) which documents the goals and objectives of the client. Perhaps the only written document parents will produce will be a rough sketch of their proposed design. Parents who lack design experience and are now required to design for novel circumstances must invent a process which will produce a viable solution.

Families felt they stumbled along, groping along a dimly lit unkown route. They grasped at possibilities when they presented themselves. We might assume that given their limited design experience and almost non-existent, design-related network, they will be less likely to generate options from which to make choices and because they are treading a new path, they will probably have difficulty in locating resources that will enable them to get the design built.

To comprehend one aspect of this phase of "scouting" I ask, what were parents' intentions as they began to generate even an informal design program? What did these parents seek? What information, or form of information, did parents find most useful? What resources did they utilize? To what extent did parents introduce changes to reduce their own chores? To what extent did they hope to provide their child with greater independence? The question of how much parents want children to be independent or the extent to which they insist on continuing "to do" for the child, caused John Moore to ponder on what the future would be for parents belonging to the MSBA who were not providing their children with opportunities to become independent. His view was that "even though it is difficult to watch them [children] struggle initially, it would be easier for the child to learn to do things gradually."

Given the hypothesis that families have a particular planning style, it becomes possible to argue that the more fatalist the planning mode, the less likely the family will be to adapt the home for the benefit of the child. The more proactive the family, the more aware the parents would be to make adaptations that would benefit the child's development as well as reduce parental chores.

Originally I had anticipated that having practical skills of carpentry and construction would probably be more advantageous for parents than having money. These expectations were borne out to some extent. If parents had seen aesthetic (domestic) barrier-free designs from which to make choices, they would have been able to put their skills to use earlier. No matter what their approach to planning, families in this study felt that as far as barrier-free design for homes were concerned, they had too few design precedents, and the examples to be found in hospitals and public buildings were institutional and unacceptable for private homes.

All couples establish a home according to design precedents dictated by their particular culture, people observe and experience such precedents at every turn (Rapoport, 1969). Couples in this study saw no models in the popular journals of Women's Day, Better Homes and Gardens, nor in furniture store displays nor among the prestigious house tours where rooms were designed by designers. Even proactive planners who enjoyed planning as an activity, and had the strongest urge to adapt their homes, found it extremely difficult to locate good information.

Some couples (Politi and Donaldson) were sufficiently "hungry" for information that they "accosted" (adult) wheelchair using strangers, to ask about their homes and housing adaptations. Couples had to piece snippets of information together into a patchwork whole. They invariably described themselves as "inventors," "explorers," and "experimenters."

Often they found the sparse information that they _had_ failed to solve certain problems. How could they adapt a house that would be comfortable now and suitable later on? What elements of the design needed to be "flexible" to allow for the child's growth and how could these concerns be incorporated into the design? How should they install bathroom fixtures, when much of the potentially useful information regarding size and to ergonomic factors generally related to _adults_?

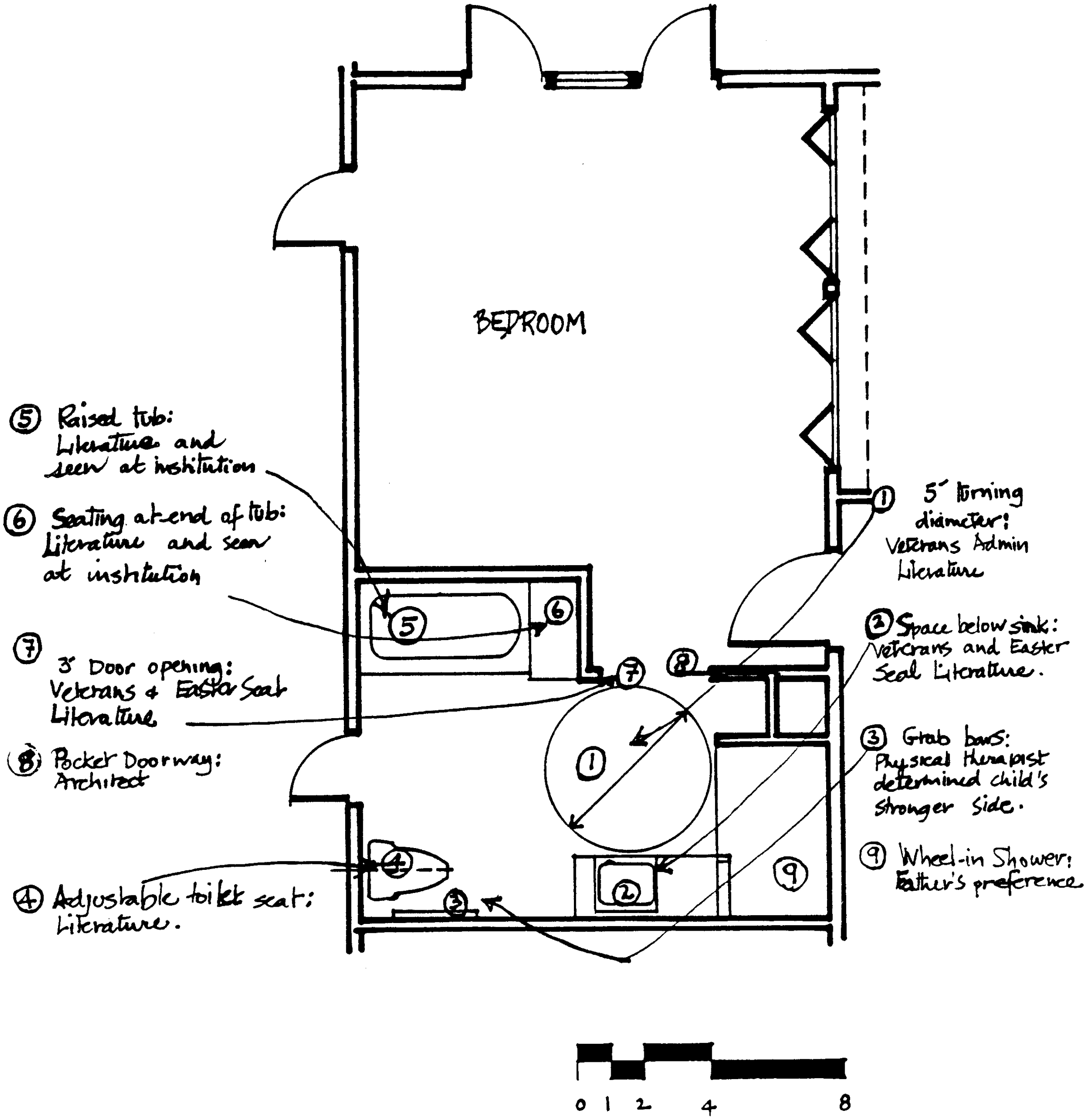
Overall, parents weighed the advantages of adapting their present homes versus finding a barrier-free house, or a house that would be easier to adapt. The Donaldsons and Simmonds families looked for alternate homes. The Simmonds found a home that was smaller, with the major living spaces on one floor. When the Donaldsons visited homes advertised as being suitable for a person with disabilities, inevitably they had narrow doorways or some steps. Eventually out of frustration and a genuine appreciation of their Cape Cod home, they decided to adapt rather than move.

The thoroughness with which people pursued gathering information varied considerably. The Donaldson family was the most diligent. Barbara Donaldson, the researcher in the family, spent two years, scouting. Despite having an academic training (she had a Masters degree in Public Health Nursing and had taught at a School of Nursing), she explained, "Initially I could not frame the questions; therefore, I did not know where to start looking." Nothing in her background had prepared her to create an enabling environment designed to support behavior for novel circumstances. With her academic training Mrs Donaldson commenced her search at the local library where she and the librarian were puzzled as to appropriate headings in the card index system. Over time, she systematically reviewed material and found twelve titles of varying usefulness.

In their search for information, this couple visited an "Ideal Home" exhibition, a residential institution, and the Adaptive Environments Center, (a resource in Boston for people with disabilities). They had a physical therapist come to their home for a consultation, and they hired an architect. They also sought (as did other parents) the advice of peers in the Massachusetts Spina Bifida Association.

Of all the spaces that require adapting, bathrooms are usually considered the most "difficult." In our society this room is regarded as a clinical necessity (Kira, 1976), and the functions that occur in this space are not a topic for public discussion. Thus, large bathrooms are viewed as a luxury item in the U.S. and because barrier-free bathrooms must be allocated more space they challenge societal norms

Plan 2: Information Sources which Influenced Architect's Design



⑤ Raised tub: Literature and seen at institution

⑥ Seating at end of tub: Literature and seen at institution

⑦ 3' Door opening: Veterans & Easter Seal Literature

⑧ Pocket Doorway: Architect

④ Adjustable toilet seat: Literature.

① 5' turning diameter: Veterans Admin Literature

② Space below sink: Veterans and Easter Seal Literature.

③ Grab bars: Physical therapist determined child's stronger side.

⑨ Wheel-in Shower: Father's preference

especially in the design of low to moderate income homes. Plan 2 and the accompanying explanation reveals that the Donaldsons gathered information from nine sources in order to design their new bathroom.

Design decision	Information Source
1) 5' diameter for wheelchair turn:	Veterans' literature
2) Space below sink:	Veterans' and Easter Seal literature, (decided they wanted a vanity not a "wheelchair" sink.)
3) Identification of child's strong side to locate the grab bar.	PT at Health Center. (Later realised that an angled grab bar would be better.)
4) Adjustable height of toilet seat.	literature
5) Raised tub.	seen at institution site visit and in literature
6) seating at tub end.	seen at institution site visit
7) 3' doorway opening.	Veterans' and Easter Seal literature
8) pocket doorway.	architect's suggestion and Carey, (1978)
9) shower.	father's preference

As stated earlier, most families had difficulty in extracting and identifying the range of activities their child should undertake, and of subsequently linking that activity with a support to be supplied by the physical setting. The Moore family had these capabilities. A list of their decisions together with their rationale appears on Table III. Table IV lists adaptations they hope to undertake upon in the future. No matter what they considered, be it grooming or safety, they tried to make the physical setting enhance their daughter's potential capabilities.

For some families (Smith, Politi, Simmonds), lack of finances in addition to the problems of scanty information compounded their problems. Parents complained that everything and anything manufactured "for the disabled" inevitably costs more than a similar item for the general public. Numerous hidden costs exist when a person with disabilities lives at home (Burton, 1975), and having to install architectural adaptations represented an added financial burden for any family. Often the small grants awarded by the Massachusetts Spina Bifida Association made the difference between getting the job done, or shelving the project. When a family required an aid such as a special stair glider, (a purchase greater than the annual Spina Bifida Association's grant), parents had to locate alternative funding sources. To defray the expense, parents needed to apply to the Kiwanis or some similar charitable organization. This tended to make them uncomfortable, they had been socialized to the American ethos that ideally (and morally) people should manage their lives independently. To be able to make such a request required that parents to set aside their traditional values and perception of themselves.

Phase 3: Design

A design process produces an outcome, a solution. This solution should, as far as is possible closely meets goals identified during the "scouting" phase. Professionals draw solutions into plans which allow various contractors to estimate materials and costs in order to build the project. Parents probably will not do so. A sketch will suffice, or a verbal description or some rough figures on a scrap of paper.

In this study all parents chose to adapt:

1) vertical access in and out of the house, not necessarily within the house.
2) closet design
3) arrangement of playthings

parents in some families adapted:

1) bathrooms
2) circulation within the house
3) interior flooring
4) exterior grounds (apart from ramp)
5) emergency exit from bedrooms.

Table II notes the design phases for which families needed assistance with design or with construction. When parents' incomes surpassed a certain level, the architectural adaptations bore little relationship to the child's disability. This repeats previous findings on adaptations of homes by adults with disabilities (Duerk, 1980).

Parents who hired professional designers learned that, although the architects were generally willing to learn, initially these professionals knew little about barrier-free design. Parents found that it was their input which insured a barrier-free home. The architects' expertise was valued because they were capable of formulating all the stated preferences into a workable aesthetic design solution, something that was beyond the parents' capabilities. A further benefit was that the architects' blueprints formalized the design requirements, so that contractors were required to build according to the specifications and removed their possible excuses "well you didn't explain that to us properly."

Parents (Politi, Moore, Simmonds) produced designs by recycling what they knew and judging new information against previously held opinions. They looked for a "fit" by balancing what they preferred with what they could afford; what would be practical with what looked appropriate; and what would produce the best "pay-off" to enhance the quality of family life. How did families produce their design solutions?

Jenny Smith had said in the interview that Graham could reproduce anything that he had seen. Surprisingly enough, even Smith, a craftsman, fully qualified in the maintenance and upgrading of college buildings, had to become involved in accommodating a returning student who through an accident had become paraplegic. The mandated process of removing architectural barriers the college meant that he consulted technical manuals and spent considerable time with the student to ascertain her capabilities and needs. According to his secretary, Smith more or less replicated the solutions produced for the student in his own home. The Smith design provides an interesting example, both because family income was in the lower range of the sample, and also because Graham knew that the design he installed would be for the family's lifetime.

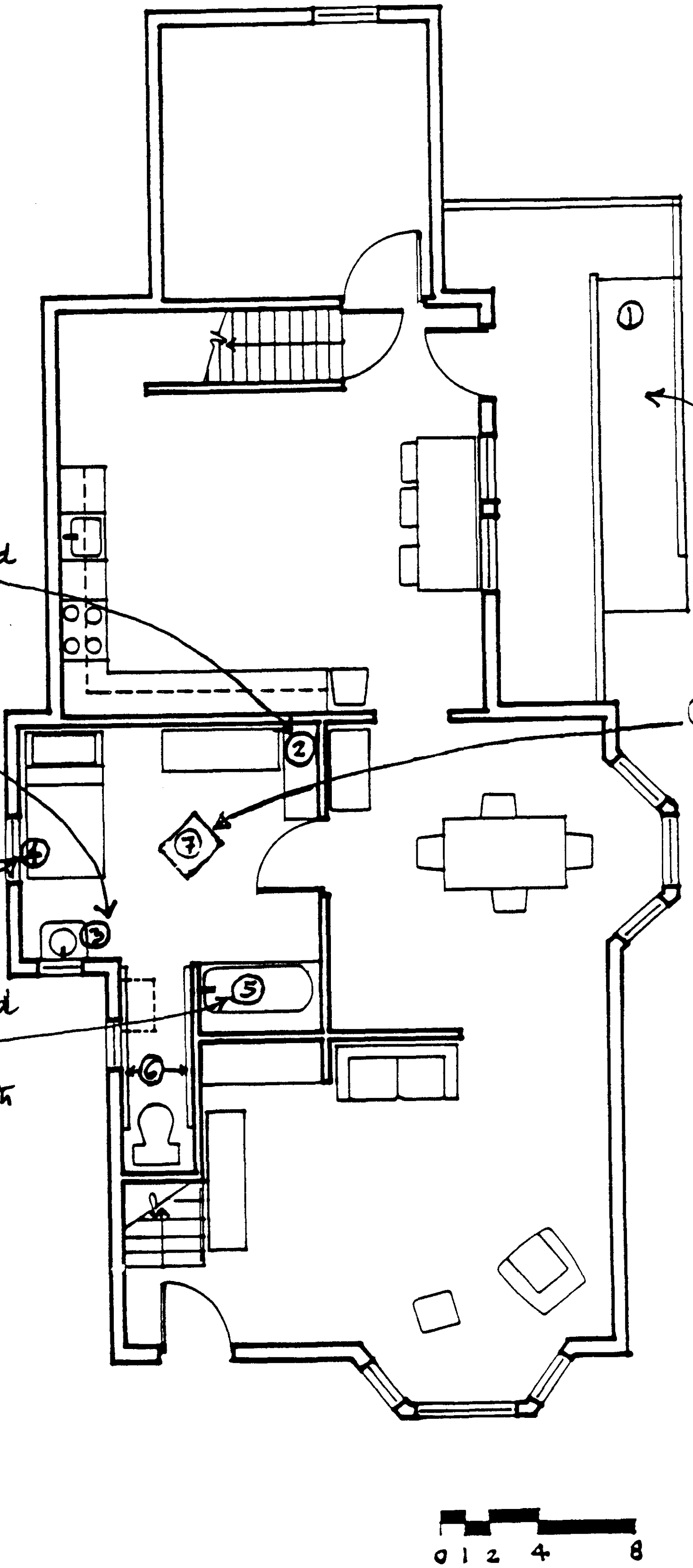
Graham Smith knew exactly what he wanted to do. He saw himself as the expert and required and sought no input from his wife or daughter. He decided that the bedroom on the first floor that he and his wife were occupying, with its adjoining toilet and hand basin tucked under the stairs would be the easiest room to adapt. The job was organized on a low budget and with the minimum amount of change. He and his son installed the ramp with the first Massachusetts Spina Bifida

Association grant, the bedroom changes were undertaken in the following year with a second grant.

His design (plan 3) shows that Graham transformed a closet into a tub with a hand held shower. The hand basin was removed from the half bathroom into the bedroom, and he installed bars along both walls the full length of the area under the stairs. He exchanged the windows in the bedroom for ones that were more easily operated.

Apart from structural adaptations, Mr. Smith did a number of other things. He used existing furniture whenever possible, or bought low cost furnishings which he finished so that they had a "custom" look. For example, he stripped and refinished Dianne's painted "childhood" furniture; added casters to the bed so that it would be easier to move and adjusted its height so that Dianne could transfer easily from chair to bed; joined a pair of unfinished chests of drawers with a single length of wood across the top and finished them to match the bed. He built an angled desk near the bed and provided open shelving around the room for Dianne to display her belongings and open accessible closet storage. He placed a television on a table with smoothly rolling casters and installed an electric bell so that Dianne could alert someone's attention in case of an emergency. Although Jennie Smith had wanted her daughter to have a nice "girlish" wall-paper in her room, her husband panelled it. In retrospect, she realized that the room will never require redecorating.

Plan 3: Housing Adaptations by Graham Smith



① ramp to driveway from rear entrance

② Hanging clothing: lowered rail, no doors

⑦ TV on roll-around table

③ sink transferred from half bathroom

④ window replaced with more easily opened windows

⑤ bath tub installed in former closet space. Ajustable hand held shower.

⑥ Hand rails along both sides of toilet area

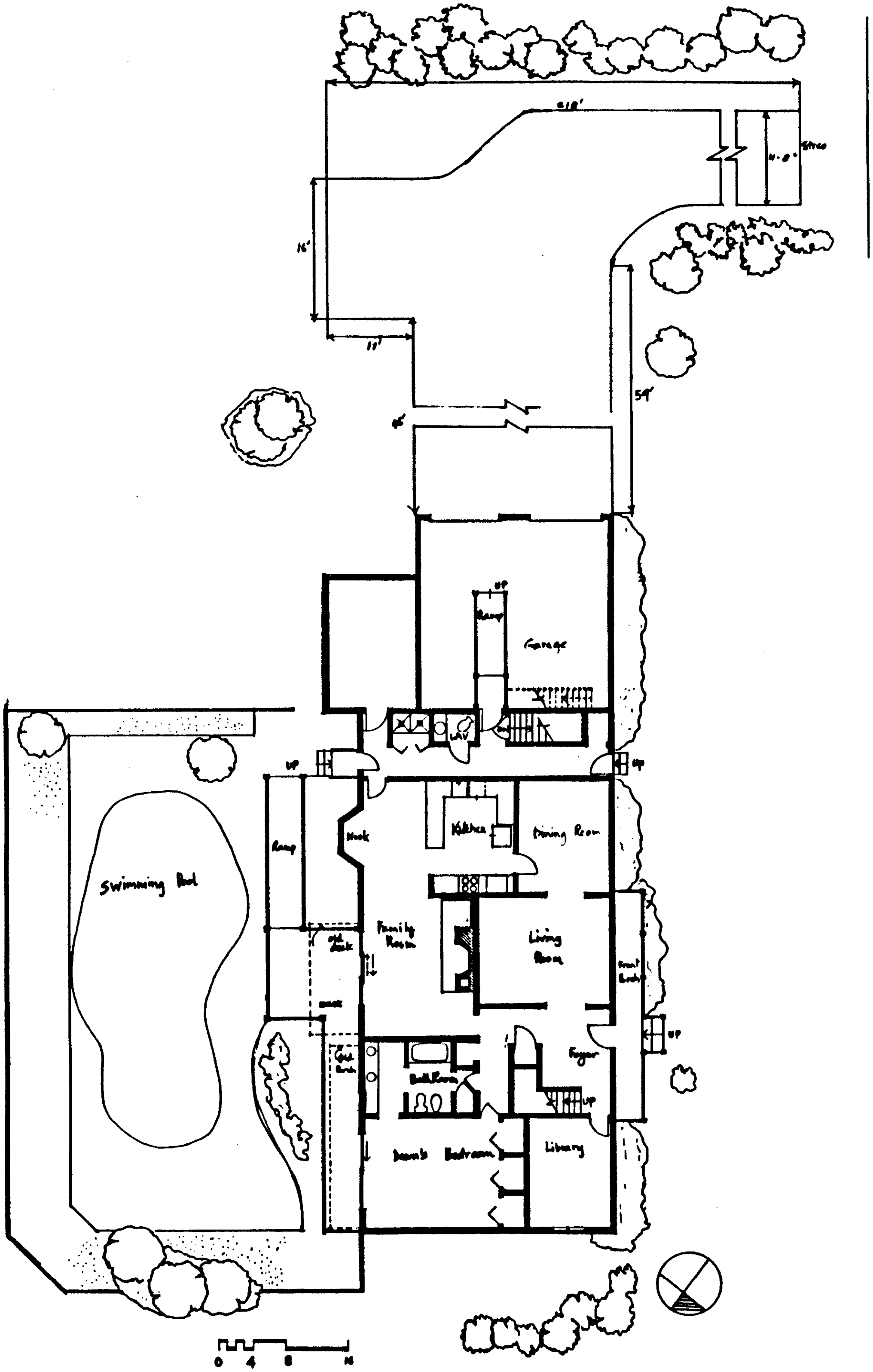
Photograph 2: Bath, Sink and Toilet Adaptations by Graham Smith

Photograph 3: Accessible Sink

Photograph 4: Clothing storage

Photograph 5: Rest, Study and TV area

Plan 4: Housing Adaptations Undertaken by the Moores



The Moore family offers a contrasting example to the Smiths, not that they were flamboyant or extravagant, however their lifestyle, budget and experience in adapting homes was considerably different. John and Sandra Moore said that once they knew their daughter was going to survive, they wanted that "as a physically challenged MOORE person," she should be given every opportunity to make the very best of her life. John once said "Kids need the independence to be able to go and they should feel free to do it when they want to." The Moores initiated making their daughter as mobile as possible when she was about two or three years old by buying her a hand operated toy "car." As she grew, they substituted larger versions of the toy. Today Dawn has an electric bike which will take her some twelve miles distance. The mother emphasized that it was only after that the parents received an official prognosis, that Dawn would be a wheelchair user could they adjust their sights and realistically consider the future.

The Moores admitted that the first time around they waited to adapt their home until Mr. Moore had a double hernia. They shifted over a period of approximately eighteen months, from being reactive planners to being proactive planners.

Dawn's independent attitude, fostered since babyhood, and reinforced by her parents resulted in the stance she took from the time she was little "I want to live on my own after I'm eighteen." This couple based their design choices on the direction of Dawn achieving her independence. They detailed their objectives and had specific concerns for Dawn's safety should there be a fire, simultaneously creating a warm home environment for the entire family.

Table III: ADAPTATIONS (MOORE FAMILY)

Number on plan	Location	Adaptation	Purpose	Outcome
1	Exterior	Ramp through garage to back door.	To shield ramp in bad weather.	Overly steep gradient, Dawn therefore needs assistance.
2	Exterior	Ramp to back deck, dining room, & Dawn's bedroom	To provide an alternate access for Dawn in good weather.	Dawn able to come & go at will.
3	Exterior	Raised original deck to level of the small porch that had existed outside Dawn's room.	To provide Dawn with emergency exit from bedroom	Dawn has access to outside. Swimmers have convenient access to bathroom & to changing area.
4	Dawn's bedroom	Installed glass doors from Dawn's room to deck.	To provide easy access to deck.	See No. 3, above. Increased light in bedroom.
5	Exterior	Installed swimming pool & enlarged surrounding deck.	To provide therapeutic exercise for Dawn.	Pool became important social center & a family amenity. Prevents social isolation of Dawn.
6	Interior	Removed shag rug & thick underpad. Finished hardwood floors.	To enable Dawn to wheel around easily.	Dawn can now wheel through first floor space independently.
7	Dawn's bathroom	Removed storage cabinet under washbasin. Replaced floor tiles.	To facilitate Dawn's use of sink.	Enhanced comfort & independence.
8	Bathroom	Purchased portable tub seat.	To enable Dawn to bathe herself.	Dawn transfers from chair to tub without assistance. She will take this aid with her to college.
9	Exterior	Had driveway blacktopped. (4000+ sq. ft.)	To enable Dawn to negotiate area, especially when on bike.	Blacktopping allows smooth wheeling, however, <u>slope</u> requires wheelchair user to exert considerably more effort.

Table IV: FUTURE PROJECTS OF THE MOORE FAMILY

Number	Location	Adaptation	Purpose
1	Porch	Raise floor, remove thresholds, & winterize room.	To add convenient space, usable year round for the whole family.
2	Dawn's bathroom	Install long-handled faucets at wash basin.	To reduce the distance Dawn has to reach (added convenience).

This family was sufficiently articulate, and goal-oriented that it was possible to ascertain their rationale for each choice, information not always attainable from other families (Table II). They made a trade-offs, weighing the relative merits of alternatives. For example they compared a covered overly steep ramp within the garage with a safely graded ramp exposed to the New England weather; an inconvenient almost unuseable cooking area for Dawn with making a change that could jeopardize the possible resale appeal of the house.

The Simmonds family designed the ramp themselves, Mel, an engineer drew up plans which included a ramp to the <u>front door</u> they were the only family to do this). Their innovative design consisted of a small square deck with a ramp flanking three sides and steps along the fourth. The family added shrubs and plants to integrate the design into the landscape. The general impression from the street is of a well designed front yard. The ramp is scarcely visible.

Photograph 6: The Aesthetic Barrier-free ramp by the Simmonds Family

Parents had too few design precedents and because of this were less capable of evaluating the appropriateness of examples they could locate, for example the Politis visited an Massachusetts Spina Bifida Association member who lived in a town house with an external elevator, subsequently they enlarged their daughter's bedroom, framing a doorway on an outer wall for an elevator opening. Over time they realised that this solution would not be viable one for their home.

Phase 4: Construction

Most of the parents possessed considerable skills for upgrading their homes. Tony Politi enlarged his kitchen, even building the cabinets. He was also finishing their summer "camp." The Moores moved cabinets under Dawn's sink, replaced floor tiles in Dawn's bathroom, and were in the process of winterizing a porch, which required raising its floor to bring it to the same height as the family living area.

In previous homes, when they had more time and energy, the Moores had installed sliding glass doors, replaced rotted out windows, and undertaken numerous other major projects. Sandra had always wallpapered, painted and furnished their homes herself. The Simmonds had removed a wall between the kitchen and hallway/dining area, installed a second-hand (straight) glider down to the basement, installed a pocket door in the basement, and redesigned an old table so that it became a display area for their son's accomplishments and toys.

In spite of these capabilities, all families needed technical information, such as the correct gradient of a ramp or how to attach it to the house. In smaller projects "do-it-yourselfers" managed alone or with the help of their kin networks (Smith, Politi, Moore). Families hired contractors to build the larger and more complex projects, although even in these instances parents tended to add the finishing touches (Donaldson, Moore).

During construction, minor changes may have to be made due to unforseen circumstances. Perhaps materials become unavailable or the child's ability has changed. In a small project, changes can be more readily introduced at this phase than in larger projects, when alterations become costly. This has implications for families working with designers and contractors. It is important that the functional and potential functional capacity of the child (and of other family members) is assessed.

The Simmonds family found a somewhat original approach for getting their design constructed. Following a neighbor's recommendation, they contacted a local vocactional-technical school. A teacher agreed that his class would build the ramp as a practicum. This local resource was especially valuable, for it meant that the family paid only for materials; the school's services were free. (There was some difference of opinion as to whether the instructor had an impact on the design.) Penny and Mel talked enthusiastically of the construction phase. It generated positive feelings among everyone, -- the students, family members and neighbors.

As might be expected, the larger the project the greater the number of complaints. Sharon Delano was amazed when on more than one occasion she arrived at the construction site to find workmen about to "build-in barriers," perhaps steps from the kitchen and family room to the deck. The contractor, (their relative) explained "Well it is only one (or two) steps." "It was" said Sharon, "proof that although family members _say_ they understand what our life is like, in fact they don't have much idea at all."

Barbara Donaldson also found that building contractors insisted that they knew what they were doing as they constructed the deck and ramp in the rear of their house. As it turned out they ended up with a step at the bottom which had to be adjusted. She found that having architectural plans enabled her to hold the contractors to a more precise agreement as to what should be installed and how it should be done.

Each of the couples used their intrinsic resources as well as they could. Those parents who had been trained during their professional lives to function in a more analytical manner than others were able to transfer this skill to adapting their homes. The families operated as open open systems. They communicated and sought assistance from their kin and community networks, and they could accept help that was proffered, (perhaps they perceived that they could provide some acceptable exchange). If the families could have seen a greater variety of models; they would have fared better.

Phases 5: Experiencing and Learning from the Design

It often took some time for projects to be completed Families, therefore, became accustomed to the new environments as they were being constructed. Families who moved into a new space or place, found benefits and shortcomings not previously anticipated. As might have been expected, neither families nor professionals made a systematic post-occupancy evaluation.

Parents and children unanimously appreciated the positive effects of the removal of barriers. "I don't know how we managed before." "Before the ramp was built I had to wait for someone (often my mother), until it was convenient, until I wasn't bothering her, before I could go out. Now I can go out by myself when I please." "I can't imagine that we waited so long." Parents, particularly mothers expended less effort, they felt relief. Parents' medical problems abated and the children gained more control over their lives. The positive responses of this study were similar to parents whose homes were adapted during a model project undertaken in Massachusetts.[2]

What did the families in this study's sample learn? These families had learned first hand of the difficulties in making their homes barrier-free. Not only did they fail to find helpful information, but sales people in hardware stores and lumber yards, usually so helpful for individuals undertaking a home improvement project would give poor advice, so that some of the appropriate information they already had would be negated. These parents agreed to participate in this study so that other families would not have to face such formidable challenges. They hoped the findings of this study would be made public in some way, so that other families similar to themselves would benefit. Individual parents who had located good resources of various kinds and were able to pass along this information to their peers in the Massachusetts Spina Bifida Association.

Perhaps the nearest data we can acquire of a post-occupancy evaluation was gained by the Moores who had lived in homes of varying styles around the United States had collaborated with professionals to build themselves a convenient home. Their accumulated knowledge permitted them to provide realtors with specific preferences to facilitate house-hunting. They wanted a good school system and a neighborhood with safe streets for Dawn to ride her bike. They stipulated that a house contain: a bed-bathroom suite on the first floor; the bathroom on the first floor to have either a 5' turning space or a second exit; at least one entrance to the house either wheelchair accessible or that could be easily adapted. They preferred a house without corridors, but should they exist, that they be either "removeable" or at least 36" wide and they narrow doorways required alteration.

Given their list of criteria, the parents explained "We always compromised by buying a house which is not completely satisfactory but had the least amount of bad things about it." Invariably they had to make some trade-offs. Every home they had bought since Dawn used a wheelchair had to have some adaptations. Table III displays the Moores' evaluation of adaptations, and areas where difficulties and inconveniences remained.

Families had concerns about compromising the resale value of the house. Mrs. Moore regretted that Dawn did not have the opportunity to prepare meals and the ensuing independence this capability offers. She described the situation as being a frustration. Dawn had strong feelings about the difficulties in the kitchen. She saw the oven location and door opening (downwards) as potentially hazardous. But the Moores would not change the room because it would affect resale value of the home. The Smiths had a similar concerns and therefore installed an adjustable shower in the new tub area rather than building one in at a lower level.

The Moores were competent to weigh the possible outcomes of various options. The parents and Dawn felt it was worth having a too steep ramp free from ice and snow, regardless of its limitations. During fine weather Dawn used the ramp through the living room.

The swimming pool, originally installed as therapy for Dawn, has proved to be an important amenity for the whole family. "The world comes to their home" as it were. Social life, play and fun was increased for each family member. The parents regarded these aspects as being especially important for a child with a disability. Their choice brought satisfaction for the whole family.[3]

The house site impacts the family in unexpected ways. The Moores went to considerable expense to black top the more that 4,000 sq ft sloping driveway to facilitate Dawn's ability to wheel on it; but Dawn reminded me that any house built on a sloped site immediately presents problems for the wheelchair user. Mr. Moore indicated that the long driveways of homes in the more affluent suburbs worked against the youngster in the wheelchair for he or she has to expend considerable energy travelling down her own driveway and up the friends' before starting to play.

When Sharon Delano initially saw the slope of their site, she was assured that it would be graded. She had not understood this term. She laughed at herself, "Somehow I thought it would be flattened out." Later she felt that the slope provided good walking practice for their son, and he has learned to negotiate it. She feels it was a bonus, because their son got such pleasure sliding down it on a "saucer" sled in the winter.

Failing to identify functions such as preparing snacks, may mean that the kitchen design will impede the children from undertaking such tasks, and reduce parents' expanding their view of the childrens' possible capabilities. Small mistakes such as a ramp ending onto a rough gravel driveway, or onto a lip that is a half an inch too high, will reduce, if not temporarily negate the effectiveness of efforts to produce a barrier-free environment.

In the Smith home, it is impossible for Dianne to transfer from her wheelchair in the tub, she therefore still has to wait for her mother <u>and</u> a neighbor for assistance. The neighbor now has a bad back. Mrs Smith is uncertain that given her current small income, and the loss of her husband's carpentry skills that she will ever be able to make the tub appropriately accessible.[4]

What did people learn from their experiences? Parents learned that they would probably never live in a completely barrier-free home, but tolerated inconveniences and modified their behavior to offset them. Homemakers conscious of maintaining the resale value of the home, tended to avoid changing certain areas of the home such as the kitchen. Families having expended such effort in adapting one home tended to feel that this would be their home for life. Perhaps the longer they remain in the house the more loathe they would be to make a change and have to undergo such a formidable task again.

The family who had gained experience and streamlined their thinking as to the necessary elements of the home identified important environmental elements relating not only to the house but also to the neighborhood. They considered the safety (traffic) and accessibility of the neighborhood, qualities of the site (non sloping), a preference of a bed/bathroom suite on the first floor, emergency exits for their daughter to manage by herself and features which would permit their child to become an independently functioning individual.

Designs and construction not thought through in detail negated, if only temporarily, efforts to increase the independence of the child. Couples learned they had "to get their act together", expand apparently bounded resources and enlist assistance from many quarters. It was extremely important that medical professionals be honest with families regarding their child's mobility impairment as early as possible, it does them more harm than good, keeping the information back for fear of hurting their fond dreams.

Kanter's quotation applies to parents of this study. They had to be masters of change, they had to reorient their activities along imaginative routes. They had to expand their resources and enlist kin and community for support. They had to their expend time, energy, money, knowledge, and effort to produce innovative change under novel circumstances.

Notes

1 An interview with Jackie Frost (December 1984), the nurse coordinator of the Myelo clinic at the New England Floating Hospital provided an interesting viewpoint. She agreed that there is a need for dealing with home environments, however, she and members of the medical team to which she belongs are surprised that parents focus almost exclusively on medical issues, and are so much less interested in wider issues which would include the psycho-social problems and architectural barriers in the home. She observed at the most recent Spina Bifida conference held in Puerto Rico that this was also the prevailing emphasis.

2 During 1984 a model program was undertaken by the Massachusetts Department of Public Health (DPH) together with the Adaptive Environments Center (AEC) of Boston. Approximately $100,000 was allocated for adapting 27 private homes where a child with severe mobility problems was living. It is thought to be the first State program of its kind in the US.

In this project, families were carefully screened, and were chosen both because of children's disabilities and because of parents' financial situation and their inability to lift and carry the child any longer. The childrens' disabilities included cerebral palsy, spina bifida, muscular dystrophy, and other similar chronic medical problems. Evaluations suggested that even if the child's independence was not greatly enhanced, removing architectural barriers often meant that it took a parent less to perform individual tasks. Thus bathing might take 30 minutes instead of an hour and a half, in addition to there being a reduction in the amount of physical effort parents expended.

A telephone interview with Sandy Lezberg of the Department of Public Health, 21 February, 1985, indicated that the final evaluation concurred with the findings of this study, that the stress families experienced was reduced, as a result of the adaptations. Also children had increased options for privacy and opportunities to be independent, and for privacy. The quality of family life was enhanced because of greater satisfaction gained from the family's ability to expend its resources of time, energy, in a more meaningful manner rather than merely completing chores.

The project director at Adaptive Environments Center, Katherine Ahern McGuiness, admitted that had she had any reservations prior to the project as to the need or value of adapting homes when children were under 16 years of age, the experience taught her that the need exists, not only for the child but also for the parents and more particularly for the mothers. Parents in this pilot program expressed their "undying gratitude." "All we heard was thank you, thank you, thank you, a million times."

3 This contrasts with the Delano family who also installed a swimming pool for their son. The husband did not enjoy swimming and Sharon found that the constant stream of summer visitors was somewhat burdensome, even expensive. They were pleased that their son had so many happy hours and benefitted from the activity, but it was not a pleasurable amenity for them as adults.

4 Unexpected benefits occurred because the work on the dissertation spanned four years and therefore contact with the families extended beyond the formal interview period, as I met with parents and children informally at the Massachusetts Spina Bifida Association monthly meetings. This allowed for a certain "catching up" as one does with old friends and acquaintences. Thus families that I first met in 1982 and 1983, I continued to meet from time to time in 1985.

At a Spina Bifida meeting in 1985 Mrs Smith and her daughter Dianne passed along the latest information about the problem of the inconvenient tub, and having to get assistance from neighbors. Jenny Smith had learned of the DPH/AEC project, applied and through an alternate funding mechanism other than the grant, the DPH installed a tub/hoist seat. The result was that Dianne gained independence and privacy, the mother (and the neighbor) also benefitted from the aid.

Chapter 4: FROM "IDEALIZED HOME" to "STIGMATIZED HOUSE"

There comes a time when a child with severe chronic mobility problems becomes too heavy or cumbersome for parents to lift and carry, and although parents had been aware of the increasing physical difficulty, frequently they refrained from removing architectural barriers until a crisis occurs. This is the result of their facing emotional as well as practical obstacles to adapting the home. This chapter concentrates on these usually ignored but exceedingly important, emotional obstacles.

I first began to develop the concept of "the stigmatized house" while teaching a course for parents of children with disabilities. An exercise requiring students to role play with their homes (Cooper, 1977) revealed the extent to which the home functioned as an extension of self -- how interwoven were the concepts of self, family and home. This relationship began to suggest why it was so difficult for class members to alter the appearance of their homes. One mother in the course wrote:

> Talking to my house is not something I do every day. Days go by without a conscious thought given to my house. Other days I find myself saying, "You're not too big, yet not too small, your bedrooms being upstairs is great! (No one can see if the beds haven't been made!) You have a cozy family room which I love, but oh, sometimes I could give you a good kick on your stairs!" I think, "what can I do other than decorating to make you a better, no easier house for my son to live in and yet keep you the house I love? Can I? How? Will you become so different (as different as the family living in you realizes they have become) that I lose the really good feelings I have for you? I hope not! I hope we can work it out." (J.S., 1978)

Similar responses from others in the class reaffirmed the theory that home is a symbolic representation of the self. Jung (1973) who had the ability to examine his fantasies and the subconscious contents of his life, built a house in incremental stages over a 33 year period, when it was completed, he realised that the final structure represented a his psychic development over time. It was a symbol-for-self in tangible form.

Fascinated by the complex meanings of "home," Cooper (1976) traced the topic in poetry, literature, and by conducting research. She came to the conclusion that "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, unchanging" (p. 447). Others have explored the the relationships between home and self

> The realization (of home) is a never-ending accumulation of intimate and subtle actions and perceptions which confirm, establish, question, modify, enrich, extend, transform, and, in other words, affect our sense of identity. (Appleyard cited by Lynch: 1978, p. 4, 1978).

Some individuals conjure images of home based upon fantasies, upon cumulative experiences of homes and other attractive places. The meanings attached to home, are generated by linking childhood memories to present experiences and future aspirations. For many the image is reinforced by projections of the "American Dream" presented through the media. This dream includes home ownership,[1] marriage, family and good health. As Americans move towards achieving this dream, they anticipate living in a progression of homes. This sequence is the <u>housing career path</u>. Individuals step onto the housing career path inchildhood. They have been socialized to expect that each successive home will be an improvement on the previous one.

Consider this scenario: A couple marry and move into a "temporary" home, with the goal of saving for a bigger and better house. This does not mean that every couple visualises the same house style or setting, but rarely would a young middle class American couple say their first home would be the one they intend to live in forever. The birth of children is a time for parents to move to a "better place," while at the end of the road they still envision their version of the American Dream, their ideal home.

Advertising agencies capitalize on, and perpetuate the extent to which the symbolic meanings of home are shared. A television commercial for Century 21 Realty portrays a child of about six years old, drawing a picture. In a later sequence the family and realtor drive up to a house, the child excitedly compares the house to her drawing. "Look, it's our house!" She knew what was considered appropriate for her and for her family. The drawing represents her family's version of the "American Dream," or an appropriate "upgraded" house to be acquired along the housing career path.

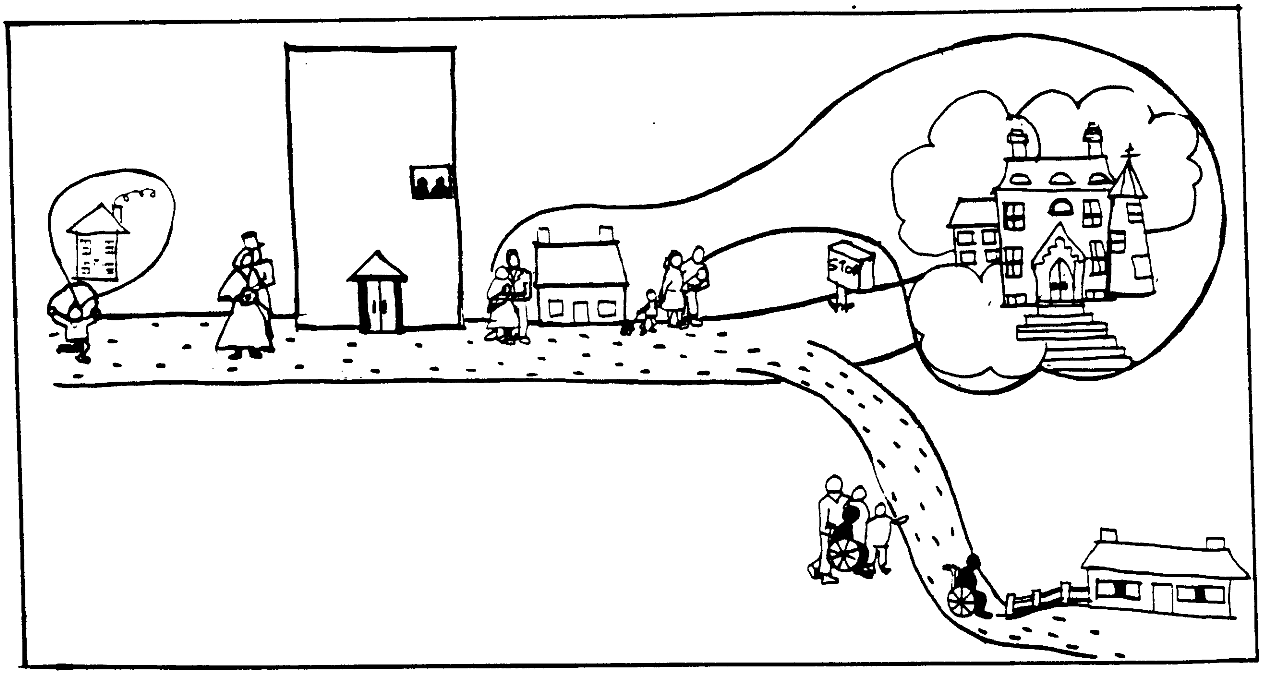
Parents in the present study had to forego their hope of the American Dream. Acceptance of their "unique situation" was neither quick nor easy. Parents admitted that before they could make architectural changes they had to accept the permanence of their child's disability, intellectually and emotionally. Families agreed that they may have "known" this during the child's first year, however, they could only absorb and accept the situation in incremental stages. As the child developed physically, emotionally and socially, parents had to reassess the child's abilities and to compare their child with other children. This, in turn, caused them to review themselves as a family. They had found that they had to re-evaluate earlier recommendations from medical professionals, to "live normally and treat your child as if he or she were normal."

Data from environmental autobiographies of mothers suggest that when they married, mothers in this sample saw themselves as being on the path of acquiring a personally tailored version of the American Dream.

Eventually though, they had to veer forever from this original goal in order to create an enabling environment for their child, (unless their "ideal" was a single level house).

The outcome at this phase of the acceptance process was that families turned irrevocably from the housing career path which would lead to their idealized house. It may be argued that most people have to compromise their version of the American Dream, it is usually possible for them to maintain their hope, that sometime in the future they will attain a home close to their version of the dream. This was not so for families in this study.

Illustration 1: The Housing Career Path Interrupted by the Need for an Accessible Home



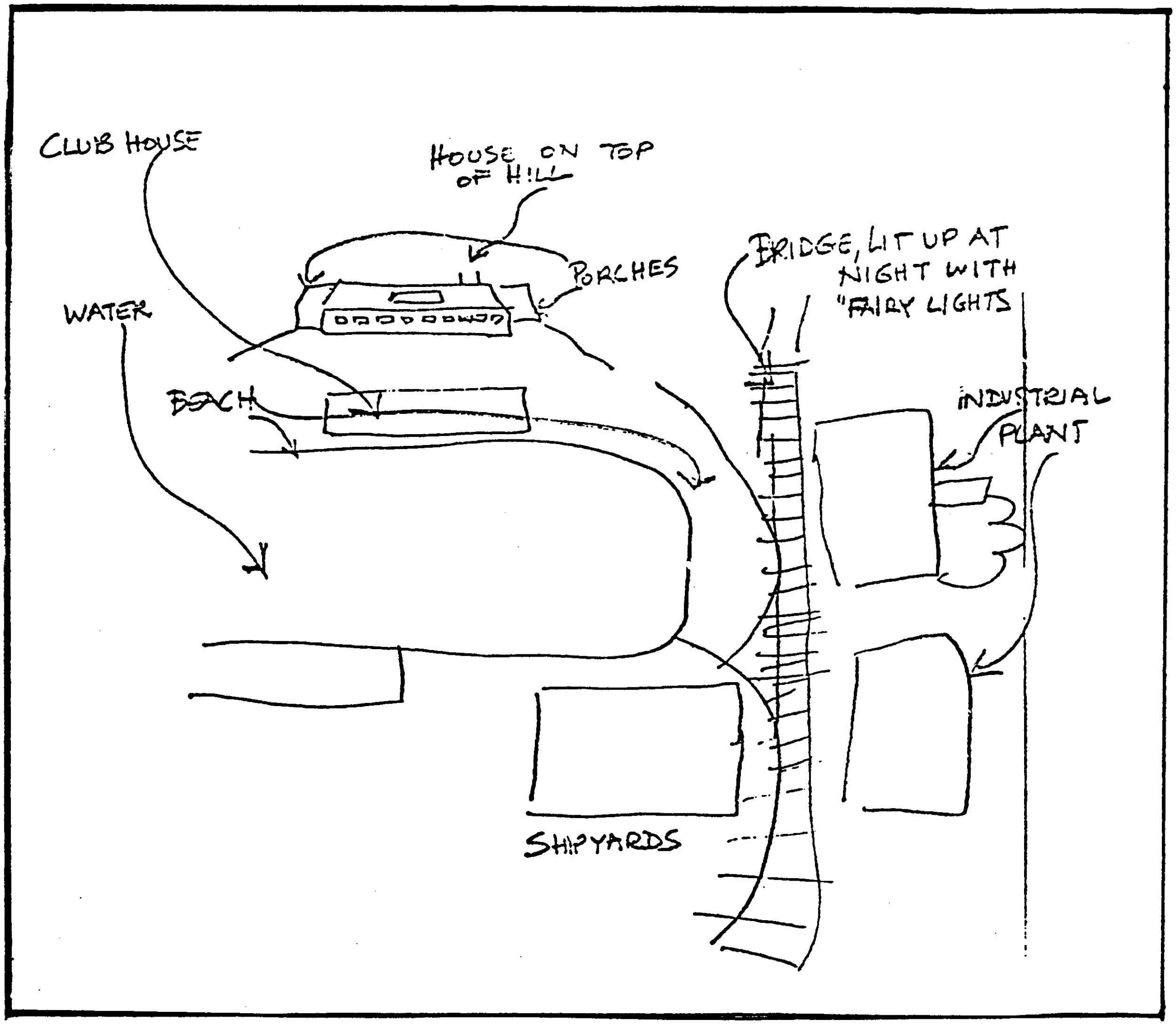
Because the meaning of home is overlaid with emotions that are rarely articulated, initially it was difficult to tap parents' feelings about changing the appearance of their homes from "normal" to one which incorporated barrier-free elements. Parents did not volunteer the information. Based on the responses parents had made in that 1978 class, I felt on safe ground to try a new approach. One day, I said to a mother in the sample, "Some parents indicated that it was difficult for them to have to make their homes look different from other homes on the street. Do you think there is anything to this idea?" There was a moment's silence. The tape recorder registered her trembling, lowered voice. She said, "Oh, yes we, too, had to struggle with that. We had to overcome our feelings. We knew what was practical, but that was not the only factor." All parents in the sample in some way or another expressed this sentiment.

Jennie Smith, a mother in the study, considered that she was at a point where she would never move. Her memories reflected the extent to which she idealized her childhood home. She had hoped as an adult to move to a similar, or even the same home, but had since given up the dream. Talking as she drew she said:

> This was a wonderful place to grow up in. We had two sun porches and I used to sit there and look out. There was always something to watch, the smoke pluming out of the industrial plants and shipyards, the boats, people on the beach and activity all over the shipyard. It was during the war and the place was swarming with people. We could go swimming, and in those days if you saw a fire on the beach at night you would go over and join the group. No one was afraid. At night time too, the outline of the bridge was lit up with lights and also by the red lights of the cars as they passed over -- it looked like Christmas all year long. (J.S. 1982)

She was living in a house different from her ideal and wistfully pointed out "I would like to live in that (childhood) house again, except that it would not be good for Dianne, and now because my husband's dead who would there be to change another house?" Graham, her husband a skilled carpenter, had found and bought the house. His logical reasoning for the purchase in no way influenced her emotional response to it. "I never really liked it. It was too close to the neighbors, there was no view and I felt hemmed in." The elements of space, water, mystery, action and

Illustration 2: Recollection of Childhood Home by Jennie Smith



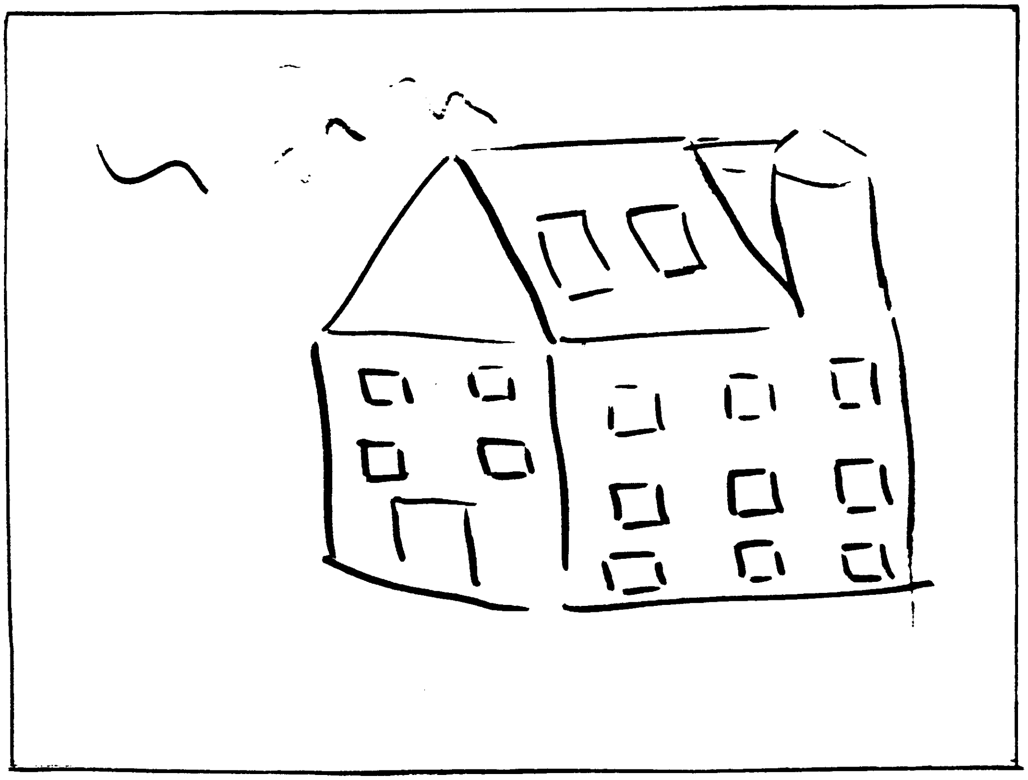
fantasy which Jennie appreciated in her childhood home, and the home she and Graham lived in as a married couple, were missing in her present home. The house was "the best one for us now" because it had been adapted. It appeared to her that it would be impossible to acquire another barrier-free home. In addition she was emotionally bound to the place, for the memories of her husband were embedded to this house.

Donna Politi spoke of her discomfort when she had to super-impose a "deviant" image on her childhood home. She and her husband struggled as they worked at accepting this new image:

> Whenever I think of "home," this house is it, the home where I spent much of my childhood and where I now live with my family. This is it. When I had to deal with changing how it (my home) would look -- to add a ramp -- that was not part of my memory of home. It was difficult. (D.P. 1983)

Donna differentiated her "idealized" home from "the best home for us now," and from the house she held dear and called "home." Her present home was not her "idealized" home. Ideally, she would live in a three-story Victorian house similar to a home in which she briefly lived as a child.

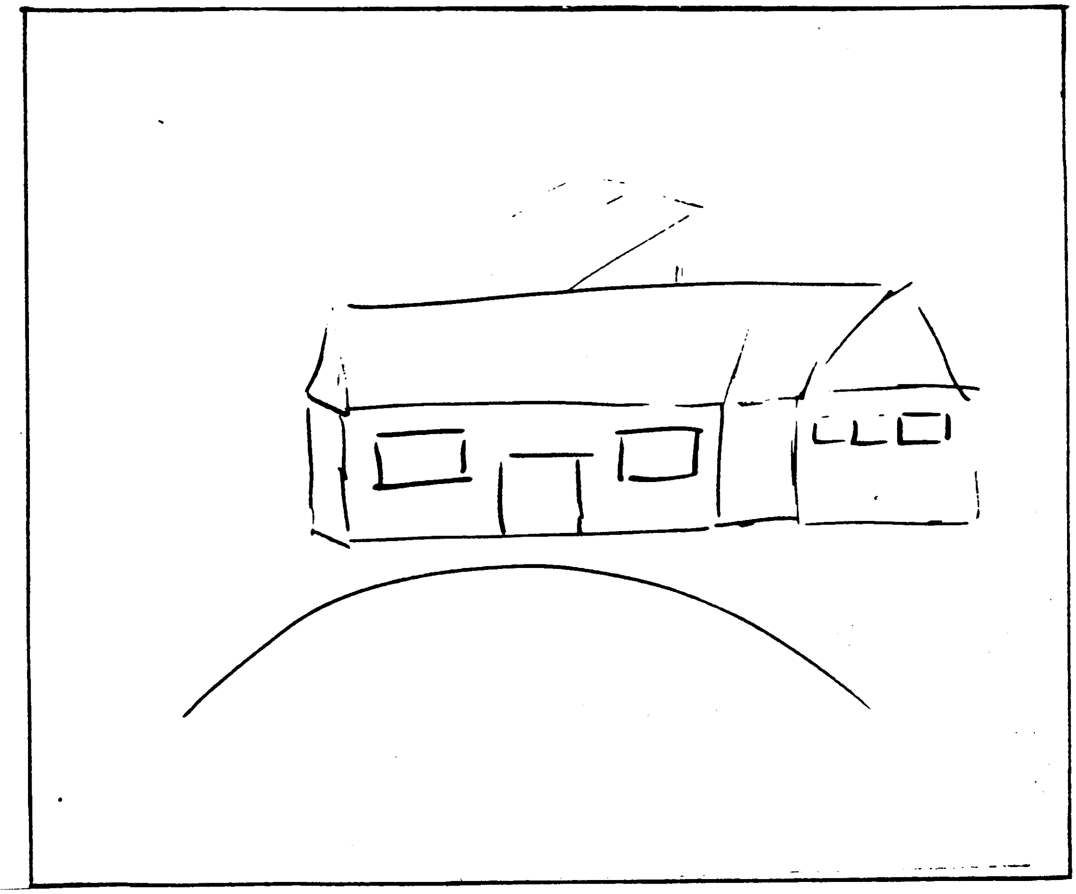
llustration 3: "Ideal House," Donna Politi



As she drew, she made these observations:

> The ideal (Victorian) home would include circular turrent room(s), a large front door, lots of space, solar panels on the roof, perhaps a flight of stairs leading up to the front door ...and of course I would like the money to be able to decorate it as I want.
>
> The perfect home for us now would be a ranch with an L-shaped floor plan. She enthused about a similar home she had seen in a nearby town. Her drawing, highlights the elements she wanted to incorporate; a circular driveway, a garage connected to the house by a breezeway. "Then we'll all keep dry." The house would have large windows and a large front door, and inside, it will be bright and sunny with plenty of space. It's unlikely that we'll ever live in a place like that for there are no such homes in our neighborhood, and Tony and I have strong ties to this area. (D.P. 1983)

Illustration 4: "The Best Home for Us Now" Donna Politi



A further example of being forced to step off the housing career path occurred in the Simmonds family. The couple had always envisioned owning a Cape Cod home with a white picket fence, so when they married and bought such a home, they were in seventh heaven. They had achieved their dream. "It was a lovely house in a nice location." Penny had been particularly attracted to the front entrance -- the hallway design and the turn of the stairs. "I could imagine our daughter, (they had no children yet), floating down the stairs for her prom with an [adoring] boy gazing up at her." Her selection of a home was influenced not only by their current needs, nor by how the house looked, but by what she imagined might happen in this setting.

When their son Josh was born, Penny's medical training forewarned them that life would include braces and wheelchairs. They knew that a multi-level house would be impractical and they moved from the house four years later. In relinquishing their dream, the couple felt that they would never again own a Cape Cod style home.

> "We realised we had to buy something that was 'good for us now.' This house is smaller, we have less privacy and space, and we're in some ways on top of one another, but it's all right. We thought it could be more easily adapted because (most of) the rooms were on one floor."

A third couple, the Moores, also abandoned the hope of ever living in a colonial style home, their ideal. They would always choose a home with an accessible first floor bedroom and bathroom, so that their daughter, who intended to live independently, could always visit them.

We might expect that a couple that had planned over the years to build their own home would have some ambivalence in readjusting their ideal design to the realities brought about by their child's physical condition.

The Delanos had always intended to build a home for themselves, and at the time of the early interviews, they were in the process of planning it. The mother's dream home was a multi-level modern home with balconies, a cathedral-ceilinged living room, a sense of openness, sunlight, and bedrooms away from the living areas.

They were building a home "to be more convenient for our son." "Homes on one level are boring," the mother stated, then as though she was trying to convince herself, "Of course, I'm very fortunate to have the opportunity to build a brand new home. How many couples are able to do this? It will be lovely, I'm sure." She felt a conflict in trying to reconcile the image she held of a home she had <u>hoped</u> to build, with the <u>reality</u> of the ranch she and her husband were actually constructing. Her dream was shattered. That it would be impossible to get back on the expected housing career path to their versions of the American Dream created a sense of loss for all these couples.

The children's responses suggested some interesting hypotheses. Usually children in the Western world when requested to draw a house, produce a two or three story, free-standing house with smoke curling from the chimney. Mark Delano (9) drew such an archtypal house. There were even a couple of steps leading to the front door. (Mark wears braces and uses crutches, so he can manage a few stairs when he has to).

Children who had <u>some</u> experience in adapting their homes featured not only the image we would expect of most children, but evidence of an awakened consciousness regarding a barrier-free environment. Paula Politi (11) drew a house similar to Mark's, except that she emphasized "The house would be at ground level so that I will have no dfficulty in going in and out, and there will be no need for having ramps." Her heavily crayoned-in large door handle is interpreted by some analysts of children's drawings as a concern with entering. Dawn Moore, (14) who had lived in many types of homes, indicated that she had dismissed the multi-story house as her ideal. She chose instead a ranch style house without ramps (her emphasis).

It would be reasonable to anticipate that children with disabilities, and more particularly those who have had some experience in making their homes barrier-free, will develop an "idealized home" which will incorporate practical qualities, to enable them to function, rather than a formal style. If this is the case, we would expect that children who have had the opportunity to experiment with manipulating environments (and are still formulating a vision of an ideal home for themselves), would have less trouble in developing an alternate "idealized" home.

We could hypothesize further that when children learn that environmental changes provide them with greater control, and when they understand that they can make the setting work for themselves, they have gained a valued skill usable throughout their lives, transferable to other settings. Dawn, whose family had adapted several homes exhibited this acquired skill. At school she initiated the removal of social and architectural barriers and was capable of ensuring that freedom was not impinged.

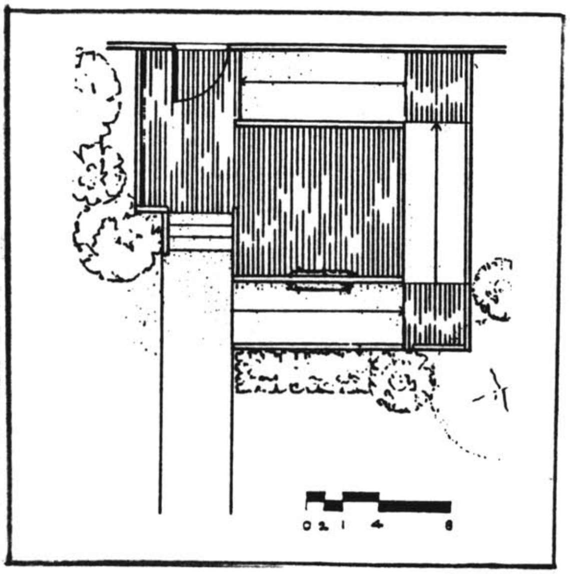
That people wish to be more similar than different from their neighbors can perhaps be seen most dramatically in the sorts of external changes parents in this study made to their houses. Of the six families studied, only the Simmonds family added a ramp to the *front* door of the house.

The remaining parents explained that ramping to the rear made more sense because it was the most convenient entrance; the entrance used by family members on a regular basis; the one nearest to the family's parked car; the entrance closest to ground level. Perhaps these were the crucial considerations. The Moores, realized during our discussions, that not once in the four or more homes where they had installed ramps, had they ramped to a front entrance. They admitted that at some level they too *were* reticent to change the image of their home. A ramp to the front door woud have signalled how they differed from their neighbors.

The Simmonds house was sited on a steeply sloped piece of land, (high at the front and dropping off some 15 steps in the rear), This fact dictated ramping to the front door. The carefully designed a ramp so as to be a positive addition to family life, the house, and neighborhood.

Photograph 7: Ramp to the front door, by the Simmonds Family

Plan 5: Non-stigmatizing ramp



For all these parents, then, part of the difficulty in adapting their homes arose from what adaptation symbolized. Parents wanted to be as similar to the rest of their neighborhood as possible, and had been advised by medical professionals to "live as normal a life as possible." They followed the advice as far as they could. In doing so they tried to hold on to the <u>appearance</u> of <u>normal living</u> for as long as possible. When parents contemplated adaptations such as adding a ramp, they knew such changes would act as a sign of the health status within the family. They felt vulnerable. They could no longer "pass" as being similar to other families in the neighborhood (Goffman, 1963). Families in the present study therefore generally refrained from changes of all sorts until circumstances <u>forced</u> them to do so.

It appears obvious that people are reluctant to alter the external appearance of their home in ways that will call attention to themselves. This problem probably applies to any individual who must adapt his or her home to accommodate a disability. Identifying the far from obvious psychological factors that inhibit a family's taking steps to remove barriers in the home might enable people in similar situations to recognize their own feelings and resolve them more readily. Recognition of the psychological obstacles linked to making the home barrier-free should also assist professionals who counsel families to empathise with their clients' concerns about "home" and all that it symbolizes. Such knowledge should permit professionals to introduce design interventions that will, as far a possible, be sensitive to issues of "the stigmatized house" and to the psychological implications of unavoidable detours or redefinitions of the "housing career path."

Notes

1 Despite high mortgage interest rates, and the inflated costs of living and housing, housing specialists consider it likely that fewer people will end up owning a freestanding home than in the past. Yet a majority of the 4,300 respondents in one study believed they would, within the next five years, purchase a traditional single-family, detached, owner-occupied house (Apgar and Wilson, 1984).

Chapter 5: SUMMARY OF FINDINGS AND RECOMMENDATIONS

This chapter summarizes the findings of the study, first by responding to the questions posed in Chapter 1, then, by discussing the overall conditions present for this population. The policy recommendations are directed to both State agencies which provide care to children and their families, and to private institutions that may or may not have a direct concern for the population. The crisp style of part one, contrasts with the major portion of the document so that those who wish to turn directly to this section may find the information with little effort.

What triggered families' decisions to adapt their homes?

- Most parents adapted their homes when they found they were physically unable to lift or carry their children any more, however parents with medical training anticipated such problems and initiated the projects earlier.
- In general, the more physical assistance available from individuals other than parents living in the house, the longer parents waited to make adaptations.

Parents responded reluctantly to adapting their homes, and most especially to altering the external features of the house. They did so only when all other options had been exhausted unless they had prior medical training.

Why did parents refrain from adapting their homes earlier?

- Parents faced practical difficulties which impeded them from taking action.

> Practical difficulties included a lack of personal resources (time, energy, money, technical knowledge), ignorance of design resources, and more especially barrier-free designs resources. In addition the medical professionals with whom they came into contact paid no attention to the architectural features of the home.

- Parents confronted psychological factors which inhibited their ability to change their homes at an earlier stage.

> Psychological factors can be traced, in part, to overcoming the shock that they had to integrate all aspects of the disability into their personal world. Families wanted to conform and to be more similar than different from their neighbors. Adapting the home represented a critical stage of accepting the existence and permanence of the disability. Removing architectural barriers meant that the couple had to be willing to impart the stigma of disability already existing within the family to the house and thus display to strangers how different they were as a family.

- Some couples realised that their dreams for an idealized house in the future were shattered by the necessity of always having a barrier-free home.

> Parents felt that even if their child eventually lived away from their home they would always want their child to

> be able to return to visit, and so they would have to continue to live in an accessible home.

What were parents' motives for changing the home?

- Parents' motives indicated a mix of reducing chores for themselves, and increasing their childrens' level of independence; however, most parents tended to emphasize one aspect more than the other.

- Parents who initiated the project when their children were pre-schoolers stated they were particularly concerned with their childrens' developmental needs which included their need to be more independent.

- Parents who embarked on the adaptation project when their children were older, were less concerned with their childrens' development and independence. They took action in response to their own personal crises.

> Parents found it painful to watch their children struggling to complete simple tasks such as dressing. It was so much quicker and easier for a parent to perform the task, especially on schooldays. Providing this kind of assistance easily became a habit.

What planning processes did parents use?

- In general, parents had few examples for setting up a design process. They perceived it as an experiment with an uncertain outcome. Not only were the specific problems pertaining to design new to them, but they were unaccustomed to defining a problem and then developing appropriate solutions. This added to their sense of anxiety about the choices they had to make.

- Parents' planning styles -- proactive, reactive and fatalist -- as evidenced during the design process were reflections of their established styles of managing family life.

- The larger the project, the more tension built between parents who felt pressure to separate their own preferences from their childrens' requirements.

- Generally, a couple exchanged ideas between themselves until they arrived at what seemed a viable solution. They rarely conferred with the children even if the children were old enough to understand the issues and to have preferences.

- The more specifically goal-directed parents could be, the better the "fit" they could formulate between actions and enabling design solutions.

- Parents who had set goals for 3-5 years ahead were able to pose more relevant questions for themselves. This made them more capable of identifying the specific activities their children should be capable of performing in the future.

- Parents retained professionals when the design projects were complicated or extensive. Professionals were either members of the family or they were known to acquaintances. Parents did not set out to find a designer who specialised in producing barrier-free designs.

- Parents made the adaptations in incremental stages, either because they lacked financial resources, and/or because they gained new insights regarding environmental design, and because the needs of the child changed over time.

Few families understood the principles of planning, most "invented"

> the process for themselves. Environmental design solutions need to be developed over the life cycle.

What architectural adaptations did parents choose?

- Parents found few "domestic" design precedents. They made choices after being influenced by seeing examples of barrier-free designs wherever they were available, in institutions, in illustrated publications, in a few homes and by speaking to adults with disabilities.

- Parents tended to copy designs that they had seen, and appeared suitable, but they had no apparent means of evaluating designs.

> Reproducing a design because someone had installed it meant, in more than one instance, that they may have chosen an unsuitable adaptation, or a suitable type but installed it incompletely for their needs.

- Complicated, large scale adaptations correlated with the socio-economic status of parents rather than the severity of the childrens' disabilities.

- Parents chose to adapt vertical access, horizontal access through the house, bedrooms, bathrooms and site (See Table II).

- Architectural changes were made roughly in the following sequence:

1. areas inside the home so that the child could use aids such as parapodia or parallel bars; entry into the house by ramp, generally to the rear door, sheltered ramp.
2. access through the house (removal of walls and high pile

carpets); storage of children's items in their bedrooms (clothes and toys); access from car to house by surfacing the driveway.

3. the relationship between the child's bedroom and the bathroom; bathrooms.
4. additional doorways to the outside (suitable for emergency exits).
5. play spaces; therapeutic forms of gross motor play and exercise (swimming pool); expanded designs which become amenities for the entire family.

> Parents made changes incrementally. Parents paid little heed to installing emergency exits, and tended to avoid changing kitchens because of the high costs. Parents had concerns about the resale value of the house.

<u>How did parents get designs constructed?</u>

- Within nearly every family, fathers had practical building and/or some design skills.
- All parents needed technical advice on design and construction such as the gradient and surface of ramps, and attaching the ramp to the house. Some fathers referred to <u>Popular Mechanics</u> or the <u>Time-Life</u> books on construction and building for practical information.

> Publications on building for amateur builders which included descriptions of tools, materials, plans and examples for specific projects such as installing a deck were considered most useful. These publications included pictures of the completed project, illustrations of the work in progress, and exploded views of details to indicate how parts should be assembled.

- Parents constructed their designs with the help of their kin network, by augmenting paid professional construction with their own labor, and in one instance by enlisting free resources available within the community.

- Half the parents required financial grants.

> Parents applied for the Massachusetts Spina Bifida Association grant (formerly $500, now $1000 in any one year) only when their financial status warranted. Parents who made extensive additions, or who were building a new home used the more usual funding sources such as bank loans to finance the projects. When parents required financial assistance that was in excess of the MSBA grant, then they searched around for alternate resources, including charitable support.

- Seemingly minor errors in detailing the design or in the contruction phase had considerable negative effects.

> A miscalculation of the ramp gradient might mean that it ended in a step, negating the barrier-free intent of the design. The child could not independently negotiate a ramp that ended in a 1" bump, or one that sloped onto a driveway surfaced with course aggregate. Parents found the professional construction workers "built-in" errors, they were inexperienced when it came to barrier free design.

What was the effect of removing architectural barriers?

- Families in this study enthusiastically praised the adaptations they had installed that "worked." They were frustrated when errors occurred. Removing architectural barriers in the home benefitted the child and his or her family, and improved the quality of their lives.

Adaptations permitted parents and children more independence. In general, families perceived themselves as coping better.

> Families' comments included "I can't imagine how we managed before." "I can't think why we didn't do this before." These responses are further confirmed by the findings of the DPH/AEC study. Administrators judged that the money and effort had been well spent, an investment in the lives of the residents.

- The children said that they had gained competence, they could control their lives to a greater extent. They could now move through the house without assistance, and choose their own activities. Other family members made similar observations.
- Children could now participate by undertaking more of the chores within the home, and they became more responsible for their personal needs.
- Parents and children felt safer.

> Children had previously felt anxiety about falling out of their chairs when being lifted up and down stairs. (There were instances where children had been tipped out of their chairs and when parents slipped on icy steps).

- Parents expended less physical effort.

> Their own medical problems abated.

- Parents and children felt less constricted as their "leash" distance was expanded.

> The children free to come and go from the house to yard no longer had to wait patiently until someone was free and willing to assist.

- Some designs were expanded so that they became an amenity for the whole family.

> When designs initiated to improve the childrens' functioning were expanded so as to create an amenity for all family members, they enhanced the quality of life. Under these circumstances family members perceived that the expenditure of resources was more evenly distributed among family members. Conversely, expensive designs installed for the child's benefit, which would not be used or appreciated by other family members, were resources willingly expended initially, but over time may cause a sense of sacrifice on the part of parents and of indebtedness on the part of the child.

Discussion

> A disabled child does not exist in isolation. He or she is part of a family group that may include parents, siblings, ane extended family members. One must meet the child's needs within the context of the family.
> Position statement of the Care of Children with Chronic Conditions and Developmental Disabilities and Their Families. The Association for the Care of Childrens Health. July, 1983.

The issues and findings discussed in this study will apply (at some level) not only to families raising children with severe mobility problems, but will probably apply to families where children have other types of disabilities (whether these be sensory impairments, mental or emotional problems, or severe learning disabilities) for whom adapting the home may appear less obvious.

Families in the sample exhibited remarkable strengths and skills. They might be considered unusual when compared with all other families, but they are for reasons noted earlier in this study especially atypical of families with a child with disabilities. In spite of the strengths (noted in chapter 2), the sample families found making architectural adaptations sufficiently frustrating that couples perceived themselves as pioneers blazing new trails.

If families with such strengths had problems, it is reasonable to expect that families with fewer advantages, whether innate or learned, would find the task formidable. This study has no information, for example about families: headed by a single parent; where a parent is out of work; where parents rent rather than own their own home (The Adaptive Homes Project, ran into situations where landlords were unwilling to install the changes); where housing is substandard and not worth adapting; where parents lacked practical building skills, or capable kin networks or financial resources to substitute for these voids; or where families were not part of an advocacy network. There is a need to undertake research with these populations to ascertain their environmental design requirements.

At this point I would like to point to an unexpected finding. One hypothesis originally posed: that it would be more likely for adaptations to be introduced when an early prognosis of the child's future could be made, appears erroneous. Spina Bifida Myelomeningocele, an anomaly visible at birth, had been chosen because of the understood medical implications of such a birth defect. Physicians have sufficient precedents to know that such children will have complex, ongoing medical problems and undoubtedly will have sufficient difficulties in getting around; that they will use braces and probably wheelchairs either all the time or when outside the home. This disability therefore appeared to offer the highest probability that planned architectural interventions would have or could have been introduced when the child was a pre-schooler.[1]

I now suspect that children who experience a traumatic accident, such as the teenager who becomes a paraplegic from a diving accident, will have their homes adapted within a short period of time, for the youngster and the parents had experienced a certain quality of life, and had based their past actions on a plan that included the growing independence of the boy or girl. Although these parents no doubt often feel guilty about certain real or imagined aspects of the accident, they never had to face the inherent guilt of having given birth to an "imperfect" child. Their goals for the future had been clearer, their expectations stretched towards "normal" options and therefore after the medical treatments had been completed and the family had understood the prognosis, they would want to reroute themselves towards achieving a portion of an originally envisioned "normal" life for their child and themselves.

No single reason explains why environmental design interventions failed to be introduced earlier by the families of this study. It appears that the dominant approach taken by medical professionals is to respond more positively to health problems that they can cure. They are socialized to be healers. Not to be able to effect a cure, or where death is the only outcome, injects a sense of failure among members of the medical profession. Physicians seemed to either foretell total gloom -- each family in this study was told soon after the infant's birth that the child would probably be a "vegetable," and would certainly have a low functioning IQ -- or gave no prognosis. Parents, therefore, had doubts as to their child's potential. The families in this study went on their own instincts and were determined to do the best for their children. Each child and family surprised their physicians. Families noted, that until physicians provided some prognosis they felt that they were unable to plan.

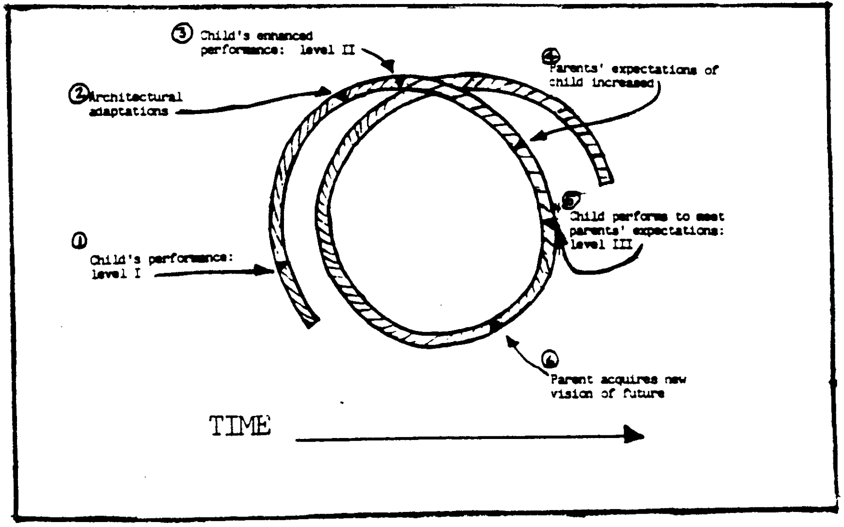
In some instances parents' uncertainty as to whether their child would survive, caused them to delay making a decision with regard to adapting their homes. This fear was renewed as the child faced many medical crises during the first 6-8 years. During the early years parents' energies were sapped by having to cope with such emergencies. Dealing with physical settings, therefore was not high on their hierarchy of needs. Lastly, not changing the environment perhaps was linked in some way to parents' lowered expectations for their child.

These latter comments in no way denigrate parents' actions or attitudes, but look towards an explanation of them. While the costs of raising a child with severe disabilities requires an expenditure of more time, physical and psychic effort, knowledge and money, than it does for raising non-disabled children, parents emphasized that through having raised a child with spina bifida they felt privileged to experience a unique love. They believed they had gained a heightened sensitivity to the value of life and acquired knowledge and friends that they would otherwise have never known.

Disregarding the architecture of the home increases the probability that parents will acquire medical problems, reduces the possibility that children will attain their potential level of independence and competence, and multiplies the strain for families whose resources are already stretched thin. The likelihood of burn-out, or of maladaptive behavior under such circumstances is intensified. We discount the fact that parents who have only seen their children functioning within a restricted setting have difficulty in envisioning them as having greater functional or social competence in an alternate setting. Parents' expectations of the child can be limited by the existing home environment, and the longer that restrictive environment remains, the more entrenched will be the perspective of the parent. The more persistent the inhibiting environment, the more the child will accommodate to it and learn a degree of "helplessness" as he or she complies with the parents' expectations and become habituated by routines.

Adapting the environment seems to reverse these trends. In an adapted environment children begin to undertake more tasks. Parents see this and expect more, children begin to perform up to parents' expectations and the cycle continues (up to a point). It was found from the evaluation of the Massachusetts Adaptive Housing program that adults outside the home -- teachers, therapists and others -- also perceived similar additional competencies.

DIAGRAM 1: ADAPTATIONS-BEHAVIOR CYCLE



Policy Recommendations

Background: Conflicting values impede United States' lawmakers from mandating family policies. Respecting the American values of individualism, humanitarianism and democracy, they fear the taint of promoting "socialistic" policies, and have ambivalence as to whether medical care should be regarded as a commodity or a right. They hesitate to place a monetary value on life or health procedures, yet this has to be done in order to produce a budget and legislation cannot but impact families' lives. For example during 1983-84, interventions in hospital nurseries required that aggressive medical care be provided for infants with severe birth anomalies, yet no proposals were forthcoming to offset the inevitable drain of parents' resources. Avoiding making policy decisions is, in effect, a policy, if not a good policy.

Evidence suggests that this country expends little effort to promote family stability, to provide preventive care, or to enhance the quality of child rearing and development. Too often, policies for poor, unemployed, or physically disabled people tend to be remedial, even punitive. An example of this attitude is the Aid to Families with Dependent Children (AFDC) program, which provides the greatest direct assistance to families. This program excludes "stable," two-parent families and a remedy to make poor but intact families eligible was defeated in 1971.

Kammerman and Kahn, (1978) suggest that family policy be formulated in accord with the principle that a policymaker should:

> Assure for each family the minimum conditions which I would want for my own if I did not know in advance what my family membership would be; or assure for each family role

> the minimum necessary prerogatives that I might require if I had to occupy it (Kammerman and Kahn, p. 501, 1978).

In attempting to formulate policy which will increase the well-being of parents and children, I urge that we view the child as a member of a family unit living in a particular physical setting, the home. The home and family must be recognized as a learning environment with inherent therapeutic potential. In the same way that academic education has been mandated to occur in the least restrictive environment, so efforts must be made to make home a "least restrictive," that is, an enabling environment.

The schema of archetypal place (Spivack, 1973) begins to provide us with a grid for comprehending the tasks and the possible settings that must be provided to support actions over the life cycle (Appendix E). To this schema Lifchez and Winslow (1979) added the environmental scales of: the intimate, the dwelling, and the community.[5] This makes it possible

> ...to draw some distinctions between the types of supports people with disabilities require at each level, and to better understand the interactions that occur there. (Lifchez and Winslow p.61)

Professionals in the medical system who interact with adults with disabilities more usually evaluate home adaptations as elements to be programmed into the habilitation of clients. The same consideration must be accorded families rearing a child with disabilities. While adults with severe mobility problems can find technical assistance and funding to adapt their homes (if they are to become income producing), there seem to be no programs for children with severe disabilities.

Based on the findings of this study, there seem to be gaps in knowledge, in policies and therefore in services. Given the problems parents face, policies need to be formulated which begin to view families in more holistic terms. I suggest that we must review the way we perceive families not only because of the population examine in this study, but also because the trend in health care, is that hospitals will in future provide care to acutely ill children, or to children with chronic illness who return again and again. Procedures will be undertaken on an ambulatory care basis, so once again parents will have to cope with unusual situations[2]. This suggests that parents need to be sent home with more instructions rather than a few lines on administering medication.

The data of this study indicates that three perspectives must be simultaneously reconciled:

a) that the unit of care must be the child as a member of a family.

b) that services for the child/family client be recommended by examining life cycle issues in addition to immediate or short term needs.

c) that knowledge of the interrelationship of environment and behavior be basic to providing services to the child/family client.

If we do this we will begin to meet the challenges of situations families now confron and being to create reasonable responses. I will now begin to sketch out from the perspective of the families in the study (or myself were I in that position) what changes might improve the quality of their lives. The recommendations are directed towards two sectors, the first being the Massachusetts State government and the agencies that provide care for children, and second for the private sector. I recognize that in some instances the actions could occur in either of the sectors, or by joint efforts.

Issues Within Massachusetts

Family as the unit of care: The tendency of government agencies is to consider the child-as-client, rather than the family and child, as the unit of care. This challenges the integrity of the family by forcing parents to try and comply with decisions and advice given by professionals who have little or no understanding of the family's culture or priorities. Such advice may force parents to neglect their personal needs or those of their other children.

Support to provide service to the child/parent unit is endorsed by the Association for the Care of Children's Health in all their position papers. Members of this international, interdisciplinary organization of professionals and parents have researched and subsequently recommended that responding to the child/family unit of care accrues social, psycho-social and medical benefits, both for the patients, their families and for health professionals.

For the population of this research, were the child/family to become the unit of care, we would expect professionals to enquire: How are you managing at home? How many hours of your day are spent in caring for this child in comparison to your other children? How does the child manage to bathe or toilet? How does the child get from the house to school? This is in contrast to the questions which are directed solely on the medical status of the child and of his or her actions with regard to physical therapy. Questions of this nature are in the realm of: How is your child managing to climb stairs? Is he or she standing upright a sufficiently long period each day?

Asking the former set of questions will indicate information as to how parents manage their lives, and when their resources are stretched almost to breaking point. Tasks that might take the parent of a child without disabilities 15 minutes may require 45 minutes with this population. When the activities of daily living are recorded in this way, new solutions and supports may become obviously necessary if parents are not to experience unnecessary burn-out. Parents may not be seeking assistance because they may not know what to ask for. This does not mean that they don't have unmet needs, merely that they may not know how to frame the question (Donaldson family).

Life-cycle Perspective: Taking a life cycle perspective requires that planning be extended beyond the immediate and short-term requirements to encompass long-term goals for the child/family unit. During certain developmental stages, most parents feel so overwhelmed that all they can consider are immediate needs. This is particularly true during infancy; however, this coping strategy becomes problemmatic when parents continue to function in this manner after the child's health has stabilizes and the child continues to develop.

Whether the child is a toddler of three who wishes to exert his or her drive for independence, a school-aged child ready to explore the neighborhood, a teenager desirous of interaction with a peer group, or young adult thinking about higher education, earning a living and establishing some sort of independent life, each stage raises new questions. Parents of all children find child rearing issues tests their competancy, however, they can find good advice from a neighbor, by reading help-columns in their newspapers, on television, and radio talk programs. In other words, it is possible, generally to come to terms with the situation by following along with what other caring parents are doing. Families similar to those in this study, need to learn how to consciously plan for the future, to negotiate how their child can enjoy new experiences and to acquire a repertoire of appropriate social behavior in response to different situations.

For children similar to those in this study, the research indicates that thought must be given to adapting the environment before the child (together with braces) weighs 40lbs. Professionals considered that it would be most beneficial to adapt homes for these children when they are between the ages of two and three years, since this is the period when their natural drive for independence appears. My professional experience suggests that there is a critical stage where it would be most useful to provide an environmental intervention for certain types of disability.

The professional counselor or social worker needs to help parents look ahead and establish directional goals -- "independence" for example -- and to then identify functions at each developmental stage and set mini-goals which will ultimately help them attain their major goal. When professionals are capable of helping parents make wise decisions for the present, based on achieving a long-term goal they will be modelling important behavior, and provide a much needed perspective. It was sad to hear parents of teenagers still talking about living one day at a time, when there was no need to cope with frequent medical crises. It does not bode well for their future.

Incorporating Environment-Behavior Knowledge: It is not enough for professionals to counsel parents based on psycho-social theories alone. The physical setting must be considered as an important variable which influences the quality of family life. At the present time, removing architectural barriers in the home for children is the responsibility of no one person or group of professionals within the medical system for this population. These professionals have not been trained to understand the inter-relationship between environment and behavior, the knowledge remains outside their domain, unavailable to them as they consult with families. Consequently they do not initiate discussions about removing architectural barriers, and therefore do not validate the issue as being of importance.

Parents rearing a child with disabilities in the home needs to be provided with adequate information so as to make the home an enabling environment. Redesigning the environment will often provide greater advantages than increasing the regimen of physical therapy (Corcoran, 1982).

Thinking of barrier-free housing for children over the life cycle suggests that we must anticipate the future. It may be that transitional housing and living arrangements away from the parental home would be a viable option during the later school years or on completing high school. Looking further ahead, we note that young adults' housing requirements have been minimally addressed. Young adults with physical disabilities have been separated from their peers and handicapped by being isolated in housing for the elderly. All too frequently they live in an enclave without adequate transportation.

Implementation in Massachusetts: Having discussed the issues pertaining to a changed perspective of care, the question remains, how can such new stances be implemented? Dramatic changes in society (such as deinstitutionalization) usually occur when pressure builds among parents, clients, and from caring professionals. Services by providers need to reorganized, and parents must become discriminating consumers rather than recipients of services.

Within the existing system, leadership in the change process must come from a government unit such as the Office of Human Affairs, or some other appropriate overriding policy-making agency. A division should be established within this office of professionals charged to view the child/parent as a unit of care living in a home, (living in the home, means understanding the environment-behavior inter-relationship) and to view the child/family requirements over the life cycle. Efforts in this division would also be towards establishing a more simple means for parents to secure services. Currently they are scattered among numerous agencies and parents have difficulty trying to locate supports and services. (It is as difficult to locate services as trying to gather ripe blackberries in the middle of a large briar patch.)

A funding mechanism for the new division might work in the following manner: The division would have its own budget which will be proportionately funded from agencies who provide care for children with disabilities. The division would be empowered to purchase services either from the existing agencies which originally provided dollars to the service or from the market place.

The intent would be to deal with cost containment without neglecting quality of care to provide compassionate services without duplication of efforts.[3] One method of offsetting costs would be to design coalitions between the public and private sectors. It would be the responsibility of an individual or group to negotiate coalitions between the public and private sectors to engage in creative endeavours (see the next section).

The existing system which provides aid to parents has no single entry point. Parents are confused as to who delivers what service, and unclear as to what services are available. While the needs of this population are complex and cannot be addressed by any one agency, it should be possible to help parents negotiate among the multiple agencies who dispense assistance. A major task of the division would be to provide this assistance.

One method would be to develop a case management system. Most parents find that one agency provides the majority of their needs. If by designating a responsible individual in this agency to the family, it would be this professional's responsibility to help parents negotiate their way among the multiple service providing agencies.

The new system would hire and train professionals to have specialized knowledge of disabilities, accessing the services providing care, and an awareness of environment design issues and resources. These professionals will deal with the complicated intra-agency actions that must be negotiated and develop a case management system to ensure that families and the State get the most for their dollar. This would mean looking at the overall picture and using preventive measures. The policy would be charged to remove architectural barriers and thus prevent the probable injury of parents, and enhance the possibility that the child will attain his or her potential. This intervention would help to prevent the necessity for a child from being placed in a residential institution. (Currently a major cause for residential placement).

A "natural" group to initiate environmental adaptations in the home, would be the teams of professionals who operate within the Early Intervention Programs. They often get to know parents within the context of their homes, and have time to build trust and rapport with families. Their contacts with parents are usually during the first three years of life but some programs last longer. It would probably be relatively easy to train this group of professionals to introduce parents to the ideas of making the environmental work well for them, rather than their modifying behavior around the existing or potentially inhibiting architecture.

The division would also have the responsibility for promoting and coordinating the specialized environmental design education relating to children with disabilities. Education would not only be directed at service providers in the system, but for sponsoring and coordinating professionals in the medical and design professions and for those in training. I could envision joint studio/course sessions where individuals from more than one discipline participate.

Curricula for professionals and pre-professionals would be developed. A need exists for audio visual presentations of various types, printed literature, course work and demonstration projects.

Research will be encouraged. Little data exist on home environments for children with disabilities. Action research projects (such as the Department of Public Health/Adaptive Environments demonstration project) as well as more traditional research methods should be initiated, coordinated and supported. It would be worthwhile to develop a grid containing children with different disabilities, families with different characteristics and different homes types (similar to that drawn up by Ekistics) and then ensure that research is undertaken in sequence according to a pre-determined list of priorities. There will be a need for surveys, panel studies, longitudinal studies and case studies on families, and studies on service delivery as the new system gets established.

Policy Recommendations in the Private Sector

It may take several years to influence Massachusetts to take action. This being the case, it is possible to improve the lives of this population by utilizing resources outside the government, or in conjunction with government agencies.

Resource Centers: (This recommendation could just as easily be in the government section, or it could be a mix between public and private sponsorship). The intention of such centers would be to disseminate information and to enable the client with disabilities in particular, would become a consumer, rather than a recipient of an aid seen only in a catalogue. The center would not only display appliances, but also room settings, so that it would be possible to see how a barrier-free environment would not have to look institutional. It would contain a library of books and visual material. It might provide internship placements for pre-professionals. Great Britain now has many such centers, I have met with their director, and have recently been consultant to a group in Rhode Island who hope to establish such a center, it can and does work.

A resource centers will support professionals, and people with all types of disabilities and their care-givers. They will display all sorts of items for people of varying ages with varying disabilities. Aids might not only be those that are manufactured for people with disabilities, but objects available in the general market place that are useful for people with disabilities. Customers would be able to try out items they know they require, and, while walking through the showroom, begin to see how other aids that they had not yet considered might enhance their lives. Such a center might make it possible to evaluate products and to give feedback to manufacturers. Showrooms such as these, will promote the development of products, and reduce the situation that currently exists, where certain manufacturers, more or less, have a monopoly on the market.

Educational materials of various types: A variety of educational materials are required to present the philosophical approach promoted in these recommendations.

a) Audio/visual presentations: Time and again parents said the preferred visual examples. A/V presentations be prepared to illustrate the design cycle from problem identification to evaluation of the design in use. These should be prepared for a range of audiences and would include parents but not be limited to self-help groups, pre-professionals of various disciplines (including designers), for in-service education or continuing education courses.

A/V presentations should be produced to teach students enrolled in technical and building programs, carpentry for example. Yet another market might be a series that could be viewed in lumber and hardware stores. (A model of this type of visual information exists in some supermarkets, where the information is geared towards selling produce.)

Television producers should be encouraged to include segments on adapting homes for individuals with disabilities (Educational Television's: This Old House). Using the public relations office of television studios mini (one minute) dramatizations should be produced to highlight how to adapt homes.

b) Publications: Easily understood, well illustrated pamphlets should be prepared and made readily available to parents and professionals. Such booklets would emphasize the process by which adaptations could be formulated in addition to possible solutions and available resources.

The development of self administered questionnaires prepared for parents and growing children, would enable them to measure the quality of their lives, and where it might be possible to make changes, and thus more bearable by analyzing their home environments.

Coalitions between public and private sectors: Creating coalitions between public and private institutions, foundations and the market place, should make possible some exciting projects. For example the participation of a major lumber-building corporation could underwrite the preparation of education materials on building. In return for investing money, the firm's staff would be educated in environmental design for vulnerable people. With staff capable of providing valid information, a new market would be made available to the firm. It would now become capable of efficiently catering to populations even outside the major metropolitan areas, something that is always a problem for people with disabilities. This would once again decentralize information and service, but allow parents to be consumers of options.

After the materials had been market tested, they could either be used in other arenas or redeveloped for new specialized audiences with the costs underwritten by another interested "sponsor."

SUMMARY

This research adopted an environmental-design approach to understand the lives of a special group families rearing a child with spina bifida. Within this sample it became apparent that architectural barriers in the home had a negative effect on the lives of family members. Removing the barriers enhanced family life in obvious and subtle ways. Parents found that as childrens' functional abilities expanded, adults, in particular, perceived them in a new light and began to expect more of the children. Responding to such expectations, there was some indication that the children began to perform according to these increased expectations. Moreover, children who have experience in making environments "work for them" gain a certain environmental literacy, so that they were able to transfer the knowledge into another arena.

Even though families in this study had sufficent positive characteristics, so that they were defined as "competent," they had considerable difficulty in trying to locate information on adapting their homes. They felt they were experimenting. Parents lacked technical knowledge, economic resources, time, and energy.

It was found that there were significant gaps in services for this population. Professionals in the medical and helping professions either ignored the environmental design issues pertaining to "home" or when they realised that difficulties were present, had no competence to solve the problem or to guide people to available resources.

All people benefit from an environment that makes them feel comfortable and capable of accomplishing their goals. People with disabilities expend greater energy than other people to accomplish seemingly simple tasks taken for granted by the general population. It would seem logical that homes for vulnerable populations be adapted so that they may live their lives without making heroic efforts to complete commonplace actions. Enabling home environments offer particular benefits in this respect.

We find so little support for children with the most obvious of disabilities, that it is not astonishing that little or no recognition is given for environmental design issues in homes of families rearing children with mental retardation, sensory losses, emotional problems, or the more subtle constellation of problems known as learning disabilities.

Architectural barriers in the home negatively affect family life. We might say that when we limit the children's abilities today, we narrow their options for tomorrow. When we increase their experiences today, we expand their horizons for tomorrow.

Notes

1 Some professionals suggested that the ideal time to deal with environmental design interventions would be when the child is about two years old. This would capitalized on the child's natural drive for independence.

2 Interview on January 8, 1985, with Caroline Smith, Nurse Coordinator of the Myelo Clinic of the Children's Hospital Medical Center, MA.

3 Catherine DeAngelis, MD, Associate Professor of Pediatrics, The Johns Hopkins School of Medicine, introduced these ideas during her keynote speech, May 26, 1985 at the 20th Annual Conference of the Association for the Care of Children's Health, Boston, MA.

4 There are instances where children remain in hospital for months, even years because insurance coverage does not pay for their needs were they to be relocated in their homes. The savings in these instances can run into thousands of dollars, but the child can only return to the home, it is adapted to accommodate the apparatus that must accompany the child. Other children get institutionalized because homes have not been adapted and because parents lack other types of support. Again the cost mounts to thousands of dollars over a year. This speaks to the tangible monetary costs and savings, and not to the emotional well-being of the family.

5 According to Lifchez and Winslow, ibid., The intimate environment includes the personal space "bubble" people carry about with them, - the bed, the wheelchair and the ministrations performed by a care attendant. The dwelling, is not only the home but "places within the community that serves residential functions - the place of work, education or ongoing contacts for social, or political, or recreation activities." The community refers to not only the physical aspects of the community and accessibility, but also the available services and supports.

Appendix A (a)

INFORMATION RELEASE FORM FOR DISSERTATION

TITLE OF DISSERTATION: Modification and Organization of the Home Environment by Families Bringing up a Wheelchair Bound Child: Determinants, Choices, and Outcomes

I understand that Beatrice Lewis is undertaking research for her Ph.D. dissertation in the Environment-Design Program of the Department of Urban Studies and Planning at the Massachusetts Institute of Technology (MIT). I understand the research focusses upon how we have made environmental changes in our home in order to provide us with an improved life style. I realize that she will be inquiring about such changes from our viewpoint as parents and from the perspective of our child who uses a wheelchair.

The information gained from this study may be used to teach designers/ architects how to plan homes for families with a disabled member; to inform professionals who provide services to families with a disabled member; and to alert families like ours how they may initiate changes in their own homes.

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 putting my initials in the appropriate boxes:

☐ ☐ I authorize the information I give to be published for Ms Lewis's dissertation, for a case study, for articles, for a book and for lectures.

☐ ☐ I authorize photographs of my children , me and my home be taken and for them to be published in the dissertation, case study, articles, a book and for lectures.

☐ ☐ I authorize my name to be used in the text and captions of the dissertation, case study, articles, a book and for lectures.

☐ ☐ 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 authorize interviews and conversations to be tape recorded, and for excerpts to be used in the dissertation, case study, articles, book and lectures as above.

☐☐

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 ______________

Signed____ date ______________

Signed____ date ______________

Signed____ date ______________

Signed____ date ______________

Appendix A (b)

MASSACHUSETTS INSTITUTE OF TECHNOLOGY
77 MASSACHUSETTS AVENUE
CAMBRIDGE, MASSACHUSETTS 02139

COMMITTEE ON THE USE OF HUMANS AS EXPERIMENTAL SUBJECTS

ANNUAL RENEWAL

TO: Beatrice Lewis

FROM: Bernard S. Gould

TITLE OF PROJECT: Modification and Organization of the Home Environment by Families Bringing up a Wheelchair Bound Child: Determinants, Choices and Outcomes

APPLICATION NUMBER: 1184

RENEWAL DATE: 5/21/82

The Committee on the Use of Humans as Experimental Subjects has extended its approval of your project for one year. Should this project be modified or terminated at any time within the next twelve months, please inform Dr. Bernard S. Gould, Chairman, Room 56-511 or Room 7-102.

xc: Susskind

Appendix A (c)

BEATRICE E. LEWIS
(332-3649)

STUDY OF FAMILIES RAISING A CHILD OR CHILDREN WITH SPINA BIFIDA

In order that we have comparable information from each family participating in the study, it is necessary to have the information from this questionnaire. I realise that this will take a few minutes of your time, but your help in providing this will be very much appreciated.

If there are any questions to which you do not wish to rely, omit them.

	MOTHER	FATHER
1. Name	____________	____________
2. Date of birth	____________	____________

3. Date of marriage ____________

4. What is the highest grade or year of school or college that you completed and got credit for?

____________ ____________

5. What is your religious affiliation?

____________ ____________

6. How many children do you have in your family? ____________

7. What are your children's names and birth dates?

____________ ____________

____________ ____________

____________ ____________

____________ ____________

____________ ____________

8. Which (if any) of these children are adopted? ____________

____

9. Which (if any) of these children are foster children?

____

____

10. Which of these children was born with Spina Bifida? ____________

____

11. Was your child born with Spina Bifida Meningocele? ____________

(with a normally formed spinal cord, but with a fluid filled sac visible on the lower back)

or with Spina Bifida Myelomeningocele? ____________

(the spinal cord failed to form a tube and the cord exists on the surface or within the wall of the sack)

12. When did you move into your present home? ____________

13. What were the main reasons for choosing this home? ____________

____

____

____

14. How many rooms do you have in your home? ____________

Bedrooms ____ Bathrooms ____ Living rooms ____ Other ____

15. How many people live in your present home counting yourself? ____________

	MOTHER	FATHER
16. What kind of work do you do?		
	____________	____________
	____________	____________
17. What other kinds of work have you done in the past?		
	____________	____________
	____________	____________
	____________	____________
	____________	____________

18. In which of these groups did your total family income from all sources fall last year (1982)? Please circle your answer.

a. Under $4,000
b. $4,000 to $5,999
c. $6,000 to $9,999
d. $10,000 to $12,999
e. $13,000 to $16,999
f. $17,000 to $21,999
g. $22,000 to $29,999
h. $30,000 or over

Appendix A - d

Interview guide for professionals
Personal Interview

Name____________________________ Date _____________________

Position_____________________
Institution _________________________________ Phone __________________
Address ____________________________________
____
____
____

Given your experience what need, if any, is there for adaptive housing for children under 18?

What kinds of disabilities warrants housing adaptations?

Do you have any idea of how many families require such a service?

Do families ever ask for information on how to adapt their homes?

Do you or any other service providers offer information on adapting the home without being asked?

How could such a service be provided?

Who would pay for it?

Given your varied experiences what policies need to be in place for housing adaptations to be provided for this population group?

Who, or which agencies should provide such services?

What are the range of changes that would need to be in place for such a new vision?

What do you think the outcome would be of this "changed world?"

Appendix B (a)

PHOTOGRAPHS BY ADULTS IN RESPONSE TO SET QUESTIONS AND SUGGESTIONS

PLEASE RESPOND TO THE FOLLOWING QUESTIONS AND REQUESTS BY TAKING A PHOTOGRAPH OF PHOTOGRAPHS. YOU MAY FIND THAT ONE PHOTOGRAPH WILL ANSWER MORE THAN ONE QUESTION. IF THIS IS SO, DON'T BOTHER TO TAKE ANOTHER SHOT OF THE SAME SUBJECT. IF HOWEVER THERE IS SOMETHING SPECIFIC ABOUT THE AREA YOU WISH TO SHOW, SUCH AS A PARTICULAR CHAIR, GO AHEAD AND TAKE THIS DETAIL.

1 Please photograph the areas in which you have made major changes in your home.

2 Photograph aspects of your home which give you
   a) the most pleasure
   b) work efficiently and function well
   c) irritate you the most
   d) don't function well

3 Photograph the parts of your home which you think other family members like best.

4 Photograph the places where your family spends most time together.

5 Photograph the location where you spend most time during an average day.

6 Photograph the places you use when you want to be
   a) by yourself
   b) alone with your spouse
   c) with other adults/friends

Appendix B (b)

PHOTOGRAPHS BY YOUNG PEOPLE IN RESPONSE TO SET QUESTIONS AND SUGGESTIONS

(Each question was on a separate page so that there was plenty of space for the respondent to place their Polaroid photographs)

Please take the photographs which you think best answer the questions and requests on the following pages. Don't worry if the shots are not great, they don't have to be. We will use them when we next meet to talk about special parts of your home.

1 There have been a lot of changes in the way your house was built, please take photographs of the changes you like best.

2. Perhaps you gave your ideas for changing some places. Photograph any changes that included your suggestions.

3 Perhaps you think that there are some other areas that still need to be changed. Photograph these places.

4 Photograph the place(s) where you spend most of your time when you are at home.

5 Photograph where you play when you are alone and where you play when you are with other people.

6 Photograph the place you like to be most of all.

7 Photograph the place in your home where the whole family spends most of its time when they are together.

8 Where do you go when you wish to be alone

9 Is there any special way you help around the house? Get someone to photograph you while you are doing this.

10 How far can you go from the house by yourself. Photograph where this is.

Appendix C

CODE CATEGORIES

The codes in this list were the original codes that were derived from the first two/three families. Over time, some less meaningful catergories were subsumed into a more major category.

#	Description	#	Description
1	Architectural adaptations	22	Envisioned future for ch.
2	" "	23	Child's functional ability
3	Aids and appliances	24	Social life of child
4	Prof. advice re planning	25	Family dynamics
5	Focus of arch adaptation	26	Balancing needs of fam.
6	Considered adpts not built	27	Personal behav mods.
7	Reason for adaptation	28	Soc supports and network
8	Most imp changes	29	Decision making
9	Aids/adptns for temp sits.	30	Routines
10	Adpts used in unexpected ways	31	How managed before
11	Changes in the future	32	Mother's realm
12	Room where fam spends most time	33	Mother's hope for self
13	Psych issues re adaptations	34	Unrecognized adaptns
14	Acceptance & adjustment re dis	35	Schooling
15	Attitude re functioning in wrld	36	Prof supports & contacts
16	Parent forced to view old age	37	Why cooperate w/researcher
17	Env. autobiography	38	Summer camp
18	Sources used to effect change	39	Parental upbringing
19	Coverage of med expenses	40	Sign events fam life cycle
20	Med problems	42	Reflectns on dsn & process
21	Fam informed at birth	43	Child rearing practices

JOINT CENTER FOR URBAN STUDIES of MIT and Harvard University
53 Church Street Cambridge, Massachusetts 02138 (617) 495-7908

Appendix D

4th April, 1985.

Dear

During our interviews I promised to send you the main description of your family. Finally, I feel that I can do this. As you can see pseudonyms have been for family members. It was obviously impossible to include all the material that we discussed during our meetings, and I had to be selective. My hope is even if your family differs now from this document, that this profile captures the image of your family as it was at the time that we met.

I would appreciate receiving your comments, and hope that you will note inaccuracies on the document and return it to me in the enclosed a stamped self-adressed envelope before the end of the month. Your pinpointing corrections that need to be made even typing errors will be appreciated.

You might be interested to hear that the Association for the Care of Children's Health will be having their conference in Boston at the end of May, and on the 28 I will be giving a presentation with Elaine Ostroff of the Adaptive Environments Center on Enabling Home Environments: Issues, Implications and Interventions. This conference offers many sessions that will probably interest to members of the MSBA.

I hope is going well with you, and that you will have a pleasant Easter holiday. Please say hello to . Thank you once again for your support.

Yours sincerely,

Beatrice E. Lewis

Encs:

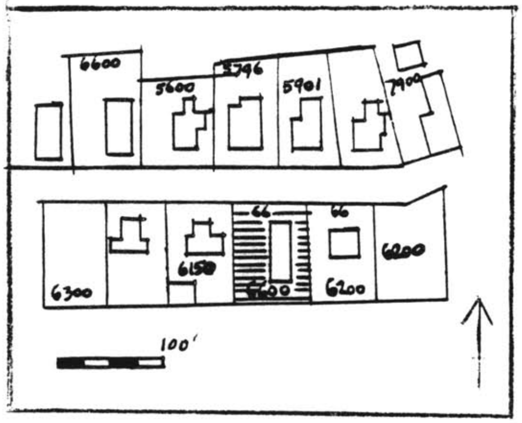
PROFILE OF THE SMITH FAMILY

Father:	Graham	58	(Died previous year). Formerly in charge of buildings and grounds at nearby college.
Mother:	Jennie	51	homemaker, sales rep for beauty products
5th child:	Ron	22	mechanic
6th child:	Dianne	14	junior high school student (spina bifida)

(four older children have formed their own households)

Photograph 8: View from sidewalk

Plan 6: Site plan



Phrases to describe this family: easy-going, casual, warm family ties, strong kinship network, acceptance of disability, modified traditional parenting patterns, fatalists, fond recollections of husband and father, good relationship between mother and daughter, higher education perceived as unimportant.

The Smith Family: The Smiths live in a modest white clapboard home on a small lot in a neighborhood of lower middle income and working class families. Graham had been a strong father figure. A feisty Scot he had left home around the age of fourteen and arrived in America by himself to make his own way. He learned carpentry, eventually he took a job at a college and worked his way up the ranks until he became Superintendent of Buildings and Grounds. He was the decision-maker for all major family matters. It was he who had chosen their house, and later made adaptations without input from his wife, indeed sometimes overriding her objections. He had strong opinions on everything including childrearing and medical decisions. He had insisted that they find a center to provide Dianne with comprehensive health care, although initially the clinic warned him that she would not be seeing the same specialists that they had been using. (They found that she only had to change one physician in making this move).

Jennie indicated that she and her late husband had had a good life together, and admitted that she was easy-going, and her husband a decisive, strong, loyal family man, who shared responsibilities in caring for the children. The couple had been founding members the Massachusetts Spina Bifida Association, for at the time when Dianne was born, very little information was available.

Although life changed considerably after Dianne was born. Spontaneous actions were curtailed, even a trip to the beach became a major undertaking. The couple always made time to get out together, and they felt fortunate that the older children were available to babysit for them.

This family did not consider advanced education to be essential. Jennie explained "All our children have done well without higher education ...I send Dianne to school, it's their responsibility to motivate her to learn." Nor had Graham thought it appropriate that his wife should earn a living, she had, he thought enough to do with raising the family, providing the means was his responsibility.

His carpentry skill was remarkable. "He had golden hands; whatever he saw he could make," recollected Jennie. He was willing to share his skiell with others and framed commendations from various aid societies attest to his willingness to build rehabilitation devices for children. Dianne would spend hours with him as he worked in his basement "shop." She still had a desire to do woodworking. She was taking a wood-working course at school, and on more than one occasion, she would be sanding a small piece as we talked.

Graham had a heart attack. When he recovered, he, with the help of his son built a ramp to the back door. A year later, he found out that he had terminal cancer. At that point he set about installing adaptations inside the house to make life easier for his family after his death.

Dianne and her father were very close. Apart from watching him in his wood working shop, most evenings he would watch the television in her room, and it was he who carried her up and downstairs to the only bathroom (before he made the renovations), and it was he who helped would bathe and wash her hair.

Jennie started to sell cosmetics from her home before her husband died, but he did not see this as earning a living. She still views the selling more in terms of providing social contacts. Computer printouts, samples, and orders ready for collection cover the dining room table and chairs, and a constant stream of customers and phone calls for this business bring the people into the house. One might say they bring the world to Dianne for few friends visit her.

Dianne is a friendly young person who uses a hand operated wheelchair. The school system provides transportation to the local Junior High, where "I have plenty of friends and dire enemies." She counteracts teasing spiritedly, and considers that teasing was a part of normal encounters not because she was a wheelchair user. She and (brother) Ron try to keep out of one anothers way since they tease and "fight" one another unmercifully, but it is he who usually wheels her up and down the ramp during icy weather.

The young people she has most personal contact with out of school are a couple of girls from the Massachusetts Spina Bifida Association families. Saturdays she swims with the Easter Seal program, afterwards she and a friend (from the program) may spend the afternoon at an enclosed shopping mall or at a movie. In the summer, Dianne may play with some very young children living on her street, but of course their homes are not wheelchair accessible, so the children must play outdoors. She has enjoyed summer camp for two years, it was a totally new experience for her.

At home, Dianne spends most of her time in her room, on the phone. Her bedroom, now directly off the living room, allows her contact with people as and when she wishes. Thanks to her Dad, he bedroom has a desk, accessible storage for clothing and personal effect, a bed casters at the correct height so that she can transfer between bed and chair easily.

She now has a "suite" with a tub, and sink in her bedroom, and a toilet adjoining her room. This bedroom was formerly her parents room, and she slept in a small rear room, but one of the major changes Graham made was around this room. Dianne still requires two people to help her get into the tub. Until recently a neighbor or her older sister would help her mother. The neighbor has now developed back problems, consequently Dianne takes fewer baths. "I don't know if we'll ever be able to afford a hoist and its installation now Graham's gone; he knew just what to do."

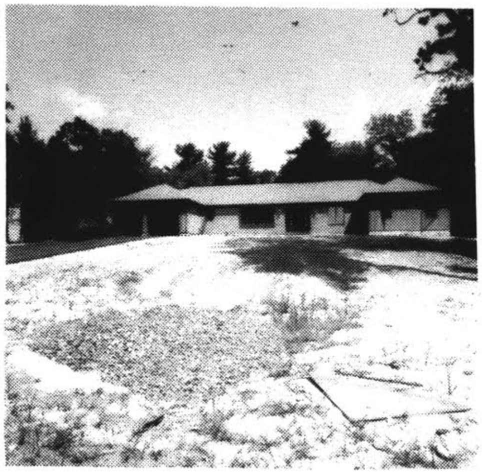
Dianne has no apparent responsibilities at home, although she is capable of making herself a snack. She appeared to be as easy going as her mother. Since turning thirteen. she began to choose her clothing for the day. Jennie considers Dianne to be the "easiest" of all her children (apart from the medical problems).

As for the future, Diane has no clear sense of what she wants to do, although she assumes that she will have a job of some sort. Ahe also hopes to marry and "have a normal baby, of course." It has been decided that some day she will inherit this house. She wonders how she will manage the two stories. Perhaps like her mother she will rent out space, "but" she wonders "How will I deal with the problems of being a landlady, if I can't get up there?"

THE DELANO FAMILY

Mother: Sharon 30 home-maker, home products sales rep
Father: Paul 39 engineer
Son: Mark 6.5 yrs. grade school student

Photograph 9: View from sidewalk Plan 7: site plan



Phrases to describe the family: affectionate, fun-loving, amibitious couple, appearances important. Parents willing to deny themselves for son, traditional parenting roles of couple being challenged. Mother deals with sorrow privately, never in public. High expectations for son, son encouraged to extend himself, also to emulate successful people with disabilties. Enmeshed extended family network.

The Delano Family: Sharon and Paul Delano are a strikingly good looking couple. Both are particularly active in the Massachusetts Spina Bifida Association. Sharon wishes to give the impression that she is a happy-go-lucky person. "When I cry, I cry by myself. [I cry] for the frustrations I feel for myself, and for my son." She almost revels that her long perfectly manicured and nails with their unchipped polish, belie the fact that she deals with diapers, additional loads of wash and many other extras that she must do because of Mark. "Sometimes people don't even believe that I'm married."

Maintaining a good appearance had been instilled in Sharon by her Lebanese mother and grandmother. This value influences several aspects of her behavior, from maintaining her personal appearance, to the way her son and home look. She believes it necessary for a woman to have a good appearance "if she wishes to keep her man happy." As far as Mark in concerned, she wants him to be tidily and well dressed. To make this possible she buys certain clothes so that he always looks well dressed. She had been upset when during the interview period he had returned home from school on several occasions looking dishevelled with his shirt halfway out of his pants. Eventually she learned that he had been toileting himself at school, something he was not doing at home.

The couple are opposed to their son using a wheelchair, and Mark echoes their opinion. "There may come a time in his later teens that Mark may opt for a wheelchair, but we feel that he should use his muscles and walk." He does so with the aid of braces and crutches. Sharon chided him for taking 20 minutes to climb the six or seven steps from garage to kitchen. In a semi-teasing fashion, she suggested that he was lazy, and would prefer to have someone help him up.

Mark a good looking, dark haired child, weighs 85 lbs. When he was tested at three years old, he was found to have the vocabulary, memory and speach of a six-eight year old, but was somewhat socially delayed. He had attended an early intervention program at the age of two, and the following year he was to a mainstreamed pre-school program. Now he is bused across town to an accessible public school, which means that he has no classmates living locally, although he does have a number of cousins living nearby. It was only this year, that Mark was beginning to comprehend the extent of his disabilities and their permanence. He was questioning his parents whether he would ever be able to dance, skate and ski.

Mark, apprehensive of most new experiences, was scared to be outside. He wanted his mother to stay with him. She explained to him that he would enjoy playing with the kids when they came over, and so he did. Eventually, they found something of greater interest in another yard and off they ran, leaving Mark calling plaintively "Kids, kids, hey come back kids. Stay and play with me." Sharon, watching the scene indoors, was in tears. Mark has a toy Kiddi Go-car, but this is operated by his legs so that he could not keep up with the children.

In the summer, a swimming instructor came to give him private lessons, so that he now swims well. For most of the year a physical therapist came twice a week to the house currently he was teaching Mark to negotiate stairs. (Learning to do this when one's legs are stiffly encased with braces appears to be particularly difficult. The individual has to gain confidence in transferring weight from one side of the body to the other, and to swing in space, up or down to the next step).

Recently Sharon had been trying to become less of a "home-body." She took on a line of products to sell from her home. She now wanted the freedom to go out with friends an evening a week, and wanted Paul to take on more of the daily chores and responsibilities for their son. Paul spends quality time with his son. Together they build models of space machines, watch television, and play games. As far as his playing with other children, it was impressive to hear Sharon describe how she had sent him outside to play.

Many family members live in the area. Each day Sharon was in contact with at least five family members on the telephone apart from calls from good friends and personal visits. Everyone is interested (and involved to some extent) in the details of the lives of other family members. Sharon's grandmother lived across the street, and this degree of contact had made the couple feel as thought they were in a goldfish bowl. On the other hand, they acknowledged that it was their family and friends who provided wonderful support from the start. A child such as Mark was perceived as being God's will, and thus they would manage.

The couple made sure that they went out together from the time Mark was an infant. They enjoy dancing and dining, and the company of friends. It was only during the interview period that they had stayed away overnight, leaving Mark in the care of his grandmother, who commented on their return "I don't know how you manage." Sharon observed, "My family keeps saying they understand what I go through, but there is no way that they can begin to comprehend what life is like. They feel for us, but they don't know." Everything had to planned for, few things could be done impetuously. Sharon described how she could never casually drop off her child at a neighbor's house if she wished to go out on the spur of the moment. There were too many detailed instructions to be given. She felt thankful that she had one neighbor who had a child with severe medical problems. This mother, was capable of taking Mark for an afternoon, and this person urged Sharon to go out and have a good time.

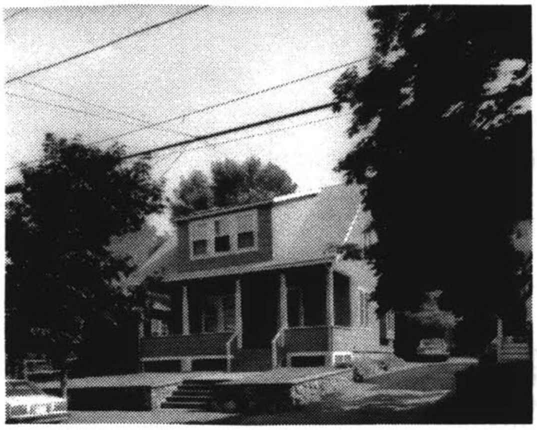
Paul and Sharon were not keen to move far away from family and friends, and were, at the time of the interviews designing and building a new home, but a quarter of a mile away from their home, on a lot they had owned for some time. The couple felt they had considered Mark in every detail in the design of their new home.

The parents discussed how complicated it was to raise a child with Spina Bifida, from the point of view of babysitting, schooling clothing, exercise and special health regimens. In spite of all this, Sharon echoed the sentiments expressed by another mother with whom she spoke several times soon after Mark's birth. This person emphasized that this child would be very special. While she could not understand this at the time, she has found him to be incredibly sensitive, aware of the feelings of others. "This child is a blessing, no matter how hard it is physically and mentally for my husband and me, I couldn't ask for a better child. I couldn't imagine living without him. I may be a little over-protective of him, and I may do a lot of things for him that I probably don't have to do, but he desrves it and repays it to me in every way."

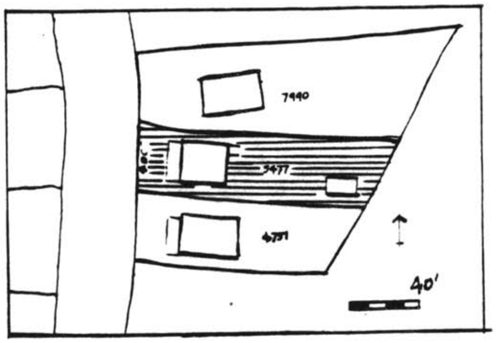
Thinking ahead, the parents hope Mark will go to college. Paul thought perhaps Mark would be a day student, "No way" said Sharon, "he'll live at college like all the other kids."

PROFILE OF THE POLITI FAMILY

Father:	Tony	42	electrician
Mother:	Donna	39	"homemaking engineer"
1st child:	Joseph	16	high school student
2nd child:	Matthew	14	junior high school student
3rd child:	Paula	10.75	6th grade student (Spina Bifida)



Photograph 10: View from sidewalk



Plan 8: Site Plan

Phrases to describe this family: affectionate bonds between family members, maintenance of ethnic and religious values, modified traditional parenting roles, strong kinship network, conscious of balancing of emotional well-being of family members, provision of social and intellectual stimulation for daughter, roots in stable neighborhood, lively social life, sense of humor, well organized, capable take action when situation demands it, mother fanatical about home-making, father a competant do-it-yourselfer.

The Politi Family: Once Tony and Donna learned that Paula had Spina Bifida they found it relatively easy to accept her, but over time, have found the physician's advice "Treat the baby as though she was normal," unrealistic. They clung to the tenet of preserving a normal appearance. "Slowly you begin to realize that you must face reality; that she is not normal." Each event: outgrowing the baby carriage, the 6th grade dance, the onset of menstruation, forced the parents to re-evaluate their situation, "...Al I'm getting older and that she's handicapped. It's an issue of acceptance."

Acceptance of an imperfect baby sister was most problemmatic for six year old Joseph. He didn't want anyone to see her and was unwilling to be seen with her. When the parents could not resolve this conflict, they sought counseling, despite their skepticism of mental health professionals.

In general the parent's attitude is, "It's a walking world and Paula has to live with that." From the beginning, the family received loving emotional support and practical assistance from the maternal grandmother who lived a few blocks away. Donna gratefully acknowledges, "I don't know what we would do without my Mom living so near." Paula and her granmother have a loving relationship. "She'd go and live with her at the drop of a hat." Apart from family support, Donna looked and looks to the parents of older children with Spina Bifida for help and advice, and in turn provides support and information to parents in the society who have younger children.

The family live in a cosy, small, three-bedroom house in the same stable working class neighborhood in which they grew up. They are emotionally tied to the locale and their friends who still live in the vicinity. They would not leave even if they found a ranch style house elsewhere because of their affection to the area and all that it offers On the first floor of their home they have a front parlor, small dining room with an adjoining kitchen. Tony had enlarged the kitchen, building the cabinets himself. In the basement there is some semi-finished space which the children use for playing games. Upstairs is a bathroom and the three bedrooms. The couple had bought land on a lake in New Hampshire before Paula was born, here they had a shell erected, and over time Tony was finishing this summer cottage by himself. All the rooms are on one level which makes it easy for Paula. Their New Hampshire home is a place where friends join them for swimming, cook-outs, it is a place where they all have a good time, and Donna happily anticipates the summer.

The Politi's emphasize traditional Catholic, Italian values of religion, family, hard work and integrity. "The family" if of prime importance. The husband's well-being rests in the hands of his wife, and when the man of the house is happy, so is the entire household. When Donna discussed their marriage, it was with warmth and affection. "I must be the luckiest woman in the world to have my husband all to myself one full day a week." As a couple, they work together as active Massachusetts Spina Bifida Association board members. They also enjoy a full social life.

Tony works the night shift in a large company. Sometimes he works overtime on Sundays for even with a salary of $30,000+ the extra income is welcomed. Most days he arrives home aroung 8:15 a.m. and either Donna cooks him breakfast or they go out to eat. Donna explained "This is the time when we talk about everything."

Donne describes herself as a fanatic homemaker. "I'm forever cleaning. I sew, write a newsletter, do craft projects, bake and so on. Yet really when I think about it I do nothing. I don't go out to work, nor do I want to. I love having the children home in the summer, but I hate the phrase "just a home-maker." Donna admitted to being a "smother

mother," who cared too much for her children. She did not push any of the children to go to summer camp. "Perhaps" she conceded "I'm more protective of Paula, ... not only because she has Spina Bifida, but also because she's by daughter and my 'baby.'"

She recognizes and respects each child's individuality. Joseph their oldest son "...would make a great 'only' child; he's shy and a perfectionist." Matthew, the middle child "is an outgoing lovable sensitive boy who has many friends and will bring home anything if it will play with him. He dotes on his sister. He will pull her around on a sled with his friends. Paula has optimism and strength."

Donna tends to weigh her life in terms of a plusses and minusses, as if it were a balance sheet. She deals with the inevitable stresses by saying, "Life's a crock," and carries on from there. She said "I fall apart, but the kid, she's fine, she bolsters me with 'Don't worry Ma, everything will be fine' or 'I can do it.'" Donna deals with school issues, but in a crisis it is Tony who keeps his cool and takes over.

All three children attend neighborhood schools. The boys are among the brightest in their classes, whereas Paula is an average student. Paula has a LD tutor 75 minutes each day, an adaptive gym teacher and an aide to assist her. A physical therapist comes to the house twice a week, and she is teaching Paul to cope with the stairs, using what Donna calls a "Frankenstein gait." Paula can manage to get around in her wheelchair, and she can also manage in a limited way to move in the bathroom for example, by holding on to available supports.

Tony and Donna Politi believe that an education (mainstreamed) alongside neighborhood children to be important, even though Paula attended a pre-school program for children with disabilities. She must, they feel, learn to live with "normal" people.

Few friends come to play with Paula at her home. Occasionally she plays with the girl next door, and would like to have her "stay over," but so far this has not happened. Even in New Hampshire, she has few contemporaries. Paula spends her time in the kitchen, the parlor in her bedroom. She loves her sunny room, an obvious "girls" room with frilly curtains and bedcovers, and a collection of Raggedy Ann doll items. Its pop group posters, hi-fi equipment and other youth-oriented paraphenalia offer cues that the occupant is moving into adolescence. A hand-operated bike offers Paula a sense of freedom. "It's heaven", she said. She cycles to her grandmother's home a quarter of a mile away.

Recently the family invested in some TV games, thinking they would improve Paula's eye-hand coordination and create opportunities for her to play as an equal with her brothers. Paula enthusiastically described the kind of fun she had in New Hampshire, where she "fishes, swimms, and bikes all around."

For a year prior to building the ramp, Donna was unable to lift her daughter because she had a slipped disc, and then Tony had severe arm problems. Paula therefore had to become more independent. She "bummed" up and down the interior stairs. (Bumming or bumping the stairs occurs when the child sits on the stairs and uses arm strength to raise or lower the body weight). When Paula reaches the second floor, she can transfer even when wearing her braces into the old wheelchair kept at this level. Paula is also capable of transferring herself to the tub and toilet, and can reach every room in the house, even if she has to crawl into her brothers' room.

Over the years, the family has introduced various changes in the home. After Paula was born, they bought a microwave oven and a dishwasher to reduce the time and effort Donna expended on chores. Five years ago, they covered Paula's dressing table with a thick pad, to make dressing Paula easier, but ramping to the back door was considered the most exciting family project.

The Politis would be the first to say that they refrain from making changes until the very last minute. They do, however, consider ideas ahead of time. Decisions for making the home barrier-free came about after noting what other people had done, for example, once Donna saw a house with a well designed ramp. She went directly to the owner to learn more about it. Donna tends to clarify her ideas by talking them over with a friend or her mother and then expresses them to Tony. The couple had seen an exterior elevator built onto a town house, they prepared Paula's bedroom for this, but over time they realized that the idea was impractical. During the interview period they priced the cost of stair gliders that would turn the corner, since the $6,000.00 price tag was beyond their means, they apprached a Kiwanis Chapter to see if they would be willing to donate some funds.

Each child has designated chores. Paula undertakes traditional "women's work." She helps cook, set the table, dust, fold laundry and unload the dishwasher. Among the children, there seemed to be the usual sibling rivalry. According to Paula, her brother did "nothing" around the house. Tony disagree, pointing out that Joseph and Matthew shovelled snow, cleaned the cars, took out trash and mowed the grass, and that they did these chores at home and also at their grandmother's home.

Life is becoming easier for Paula's parents. The amount of direct care they have to provide her is tapering off somewhat. Paula is learning to catheterize herself. On the weekends Paula sometimes selects her own clothes and dresses herself -- no easy task for she cannot bend over when wearing her braces. Dressing takes about 30 minutes. Until Paula started to menstruate, Tony helped her with dressing and toileting. Shamefacedly Donna admits, "Sometimes I feel that if I have to change that child one more time, I'll scream."

As to the future, Donna thinks Paula will hold down some job, but is unsure what it might be. She also expects Paula will drive a car. Tony is unsure. "It's hard to say. She'll always require a certain amount of care; on the other hand, she has a lot of physical strength, so you don't know."

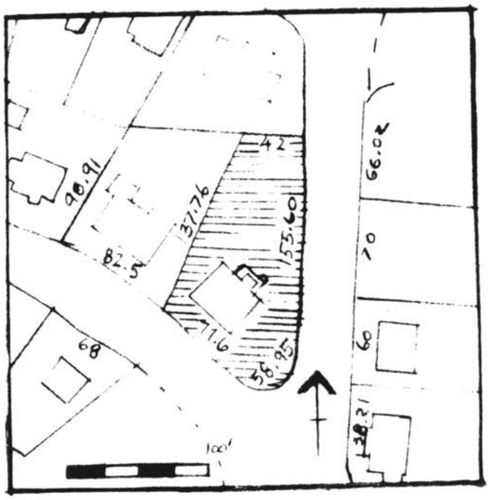
Paula's goal is to become a homemaker like her Mom. When Donna pressured her on this question, she eventually responded, "Well, perhaps a nurse or a teacher." No mention was made of Paula living independently. "In fact, there is no sense in worrying about the future, because there are so many other things going on [with her]," explained Tony.

THE SIMMONDS FAMILY

Father:	Malcolm (Mel)	41	civil engineer
Mother:	Penny	38	home-maker, x-ray technician
1st child:	Barry	13	junior high school student
2nd child:	Josh	10	student at special school (spina bifida)

Photograph 12: View from sidewalk

Plan 9: Site plan



Phrases to describe the family: collaborative, sharing, loving, firm, assistance in home-making by father, sensitive, support from kin network, outdoor activity enthusiasts, realistic planners, do-it-your-selfers, concerned about the future, consciously balance family members' well-being.

The Simmonds Family: Penny and Mel's home located on a tree shaded street, is near to Mel's job so he returns home most days for lunch. The grandparents live a few blocks away. Penny and Josh, with the aid of a walker instead of his wheelchair, can "walk" to their home. Their family and friends help out by providing moral support and babysitting.

Eighteen months before our interview commenced, medication caused a series of seizures which severely reduced Josh's mental capability. He had to relearn how to tal. He now functions at the level of a six year old and his parents have little sense how much intellectual ability he will regain. His future is uncertain. Josh now attends a special school outside his town.

Dark haired, dark eyed Josh, was described by his mother as a personality plus kid. He's always sociable and has a ready smile. His father feels his winning manner will always be an asset. When in hospital, for example, he always has a "hello" for the nurses, because of this they respond and treat him as a "favorite." Josh reach out to touch a person's arm, and looks deeply into his or her eyes, as though he was trying to "read" them completely. When engaged in a task, he seeks frequent approval and encouragement. Josh requires help with most aspects of life including dressing and grooming. Nevertheless, Josh's parents give him responsibilities, such as taking care of the dog, vacuuming the living room or loading the dishwasher. Penny deals with Josh firmly but lovingly. When she makes a request, she expects him to comply and carry it out, and quietly insists that he do so.

This couple felt fortunate knowing from the beginning that Josh would always need a wheelchair, braces and a walker. His parents started dealing with architectural barriers "early" in order to help Josh become as independent as possible. Their premis being "We try to keep life as normal as possible and to keep the home the same way. We want our home to be <u>our</u> home, but functional for Josh."

Barry, Josh's brother an outgoing friendly boy explained, that his brother does what he can and that he was getting to be more independent. Barry believed that having Josh as a brother has taught him to be a more understanding person. "You know better than to stare at people who are different." Barry is active, he is an enthusiastic Scout, had recently taken on a paper route, and enjoys sports. As for school, he told me, "School's a bore, but how interesting can it be anyway?"

Barry was the family's first-born child, but before Josh was born they had a still-born child with birth anomalies. They grieved about this infant's death, and explained the loss to Barry in as simple a way as they could. Subsequent information for the parents provided by a genetic counselor was too vague to be helpful. Later when Josh was born, they shared with Barry what had happened, and explained that this baby had certain problems. "We're more open than my parents were about death and feelings. We have no secrets, and let Barry verbalize his feelings -- perhaps too much -- but feel this is a healthier state of affairs."

Penny works one or two evenings a week in a nearby hospital but considered changing her career. "It's too much working with sick people in the hospital and then coming home to a child who is unwell." Mel works for their city's engineering department, he takes an active role fathering their two sons and helping his wife. He assists with caring for Josh, and "holds down the fort" when Penny worked her 4-11 shift.

Last year the family wanted to go camping, so they enrolled Josh in his school's summer camp, the rest of the family had a wonderful trip, "But" said Penny "I really had twinges of guilt." As it turned out Josh thoroughly enjoyed himself, rather than feeling left out, he felt more similar to Barry who goes camping with the Boy Scouts.

Most winter weekends the family go away with a ski club. This group in some ways relieves the parents of the sole caring of Josh. They provide Josh with a larger social circle although Penny found herself "over vigilant", fearing that he might ruin the childrens'games. Her husband was more likely to let the children work things out for themselves. Her concern arose from ther perception "There is no broad basis for friendship with other ten year olds, in fact it's hard for these children to have friends, they tend to live separate and sheltered lives." Even at home Josh tries to play with Barry's friends, for he has few friends of his own, however, given his mental ability he plays more frequently with the neighborhood children much younger then he.

Penny emphasized the difficulties of parenting a child with such disabiltiies. It is impossible to compare Josh's development with parents who have average children. Now there is also Josh's uncertain future. As she spoke of these issues, she volunteered, "It was easy to accept Josh as a baby, but it appears that there are different levels of acceptance. For example, Josh is ten now and just beginning to read and write <u>letters,</u> just beginning to interact with kids and that hurts (again)."

Raising Josh meant coping with hidden expenses for braces, foods, car expenses, medications, clothing, washing powder, apart from costs of home adaptations. The major difference in thinking about the boys' futures appears to be "I don't plan ahead with Barry particularly, he will take care of himself afterwards, he will have his difficulties, but he will survive, he will manage. Josh might not survive, or his life will be very, very difficult. It's scary. We want to think that he'll be able to take care of himself. We'd like him to get a job in a normal setting, perhaps a restaurant, and because he's an affectionate person he would enjoy the companionship of being married, but would he be capable?"

The parents believed they manage well as a family because they "functioned as a unit, where individuals work together and take the lead when this is appropriate." Mel and Penny sensitive to the other's moods, each try to reduce pressures on their partner. Mel might take the boys for a meal, and Penny would do something similar for him.

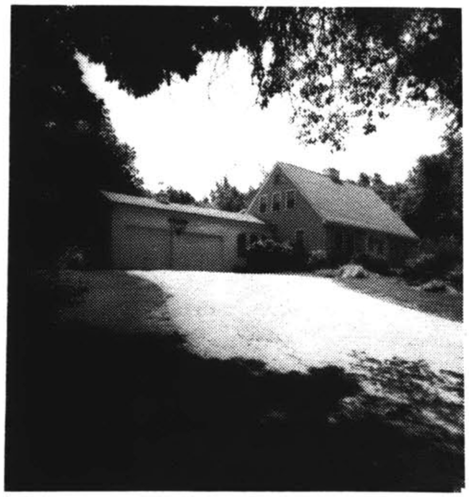
The parents try to balance the needs of individuals in the family and to minimize the amount of attention focused on Josh. For example, Penny monitored her responses to peoples' inquiries in a single sentence, "...for the whole conversation could revolve around Josh and his current problems, and that's not fair to the rest of the family." When Josh has to remain in hospital, his parents do not stay overnight with him because it disrupts family life so much. We visit him each day and he copes well." Barry admitted, "We miss him when he's in hospital, but know he's in good hands."

The sensitivity and compassion exhibited by Mel and Penny have been absorbed by Barry. When Josh was having seizures he made distressing moaning sounds all night, the parents monitored him, and they got exhausted. At one point, Barry urged his parents to let Josh sleep in his room, so that they could get some rest. This does not mean that there have not been times when Barry has felt less than giving towards his brother. "Sometimes I care that a lot of fuss is made of Josh, but I get attention too. My parents treat me more like an adult."

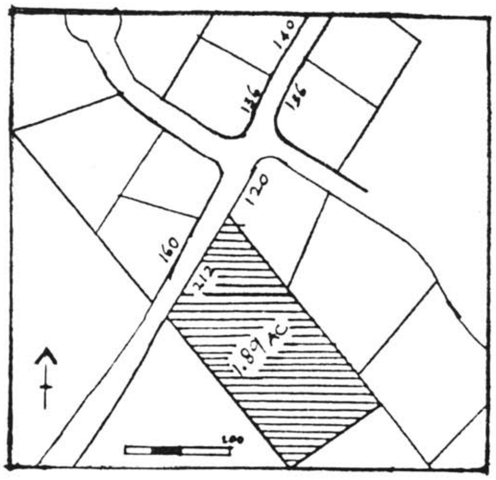
PROFILE OF THE DONALDSON FAMILY

Mother:	Barbara	39	Home-maker, former professor of public health nursing
Father:	John	46	Sales representative
first child:	Julie	6	kindergarten student (spina bifida)
second child:	Matthew	3.5	part time nursery school (adopted)

Photograph 12: View from roadside



Plan 10: Site plan



Phrases to describe the family: homeloving, caring, serious, conscious of lost dreams. quietly competent, persistent, hardworking, independent, coping with frequent medical crises, limited kin network and social life, husband and wife have contrasting styles of managing.

The Donaldson Family: Life has not unfolded as they had anticipated when they married nearly three years before Julies's birth. Their marriage started off with what appeared to be great advantages. Said Barbara "We were fortunate, because we had more savings than most newly-weds, because we were older when we married, and [because we] had established careers."

Barbara and John shared significant values. As Catholics, they both tried to attend Mass once a week after which they might have a weekend meal with his parents. They were college graduates, and Barbara had a graduate degree in nursing. They intended to establish a loving, comfortable, well-appointed home in which to raise children.

The Donaldsons discussed buying a house as they made marriage plans, and spent time looking at houses together, but it was John who called her at work to share the news "I've found our house!" The house they bought was located in the town John had grown up, and where his parents still lived. When she saw the Cape Cod house with its pleasingly landscaped front garden, its large old trees, and rear yard was Barbara's responded with "It immediately felt more like a home than a house."

Apologetically, the Donaldsons explained that they were in the middle of a big experiment (the adaptations were still in process) and did not know whether they would be of much use to this study since they had no idea how the adaptations would work out. To passers-by, the house looks the same as ever, little of the extensive renovations are visible from the street. The couple added a new bedroom-bathroom suite on the ground floor, renovated a guest bathroom, enlarged the kitchen by incorporating a sunny family room with access to a deck and ramp through sliding glass doors, and installed solar energy units to heat their water. Barbara laughingly pointed out "Now because we have made so many changes we have built a geriatric home for ourselves."

They only embarked on these extensive renovations after an unsuccessful search for a barrier-free home which lasted two and a half years. They would have looked at anyone's home had they known people who had removed architectural barriers for someone (particularly a child) with mobility problems.

When considering changes in the home, the Donaldsons stated that they made decisions regarding the decor of their home by weighing convenience, aesthetics and the degree of assistance it would provide Julie. They considered that "captains chairs" would look nice and homely and, at the same time provide good support for their daughter. Julie had been sleeping in a four-poster bed since she was three, for its height made it easier to tend her.

Barbara and John described themselves as a private couple who led a quiet life out of choice. They preferred an evening curled up reading to some other forms of entertainment. They had a few good friends, people they had known for many years with whom they like to spend time, and Barbara tried to maintain her professional contacts. They used to enjoy fishing at the Cape at his family's summer home. They still spend time there, but because of the children, Barbara could no longer sail off with her husband on his boat. Their devotion to their children left them little time solely for each other, and during the interview period, they arranged their first weekend away from Julie and Matthew.

Barbara admitted "I am paranoid about Julie's care. If for example I don't pay attention to ensuring that her bladder is completely emptied, she will get an infection then she and the whole family have to pay for it." She found it difficult to locate reliable babysitters for Julie, either for the day or for an evening or for a longer period of time. Julie required specialized attention for toileting, bracing, dressing, exercising and care during the night. Barbara attributed her watchfulness to her medical knowledge. Julie had been in hospital six times during her life at the time that the family was first contacted. These were for varying periods of time, the longest being six weeks. Whenever she was hospitalized, Barbara stayed overnight with her. (During the data gathering period, Julie had several more hospitalizations).

The couple had faced serious problems, but they seemed to transform problems into challenges for which acceptable solutions could be generated if only they searched hard enough. Evidence of this tenacity of purpose is to be found in the design for their new bathroom, where the couple accumulated ideas from more than nine sources.

The parents used a similar approach when confronted by other types of difficulties. They were dissatisfied with the stance taken by local medical specialists, they therefore chose alternate medical professionals in Boston (approximately 70 miles away). This meant that they must travel more than an hour each way for office visits and when Julie is in hospital, must commute hours instead of minutes to spend time with her.

The couple favored contrasting styles of planning and managing. John, the "doer" in the family, felt that Barbara, the "researcher" read too much. She considered that his method of "jumping-in" and attacking a job, with some trepidation. They, (mostly she), spent two years assembling information about removing architectural barriers. The meshing of their styles of tackling projects probably provided a good balance between investigation and action.

Before her marriage Barbara taught courses in public health nursing, she retained her professional status by taking the necessary continuing education credits each year, even though she had difficulty in finding adequate baby sitters. Although she hoped to return to her professional life, in what seemed like the the distant future, for now she took pleasure in being a creative home-maker. She thoroughly enjoyed cooking and baking (she baked goodies, if only to surprise a neighbor). With regard to the renovations she began staining and painting the interiors until Julie's medical problems reduced the time and energy available to her. Finally, they had to hire someone to complete the work.

As a sales representative, John was responsible for a large territory which took him away from home about three months of the year in stints of nine days at the most, but generally he was away for two or three days. Barbara found that she was super organized during his absence, more likely to get the children to bed on time and to finish her chores.

At home, John played a decisive role in the choosing of home furnishings, wallpaper and fabrics. He shared in homemaking by marketing, playing with the children, tending the garden and raising vegetables. He spent more time with Matthew than Julie, and had begun to realise the amount of affort it took to get Julie ready at the start and end of each day, and was beginning to assist in the <u>chores</u> of child rearing.

Life within the family was fraught with medical crises, so much so that it was difficult, if not impossible for Barbara to describe the routine of their life. Eventually she identified that most days hours had to be spent providing direct assistance and care for six year old Julie compared with less than an hour for three year old Matthew. The couple conscious of Matthew's needs, tried to compensate for the imbalance of time that Julie's care necessitated and to help him adjust to conditions caused by the chronic and acute medical problems of his sister. "Our life" Barbara explained "is altered by medical crises, and what occurs during or after an episode is different from what went on before." This type of sense of a lack of routine and order to life is fairly typical for families rearing a child with Myelomeningocele during the first six years of life.

Appendix E

Archetypal Places

GENERALLY RELATED LIFE CYCLE STAGES

A	B	C	D	E	F	G
INFANCY: Reflex control; orientation; communicate with siblings and parents.	CHILDHOOD: Gain motor, social, verbal, intellectual, emotional competence.	ADOLESCENCE: Forge identity; establish peer group regulations; social/sexual exploration.	COURTING-MATING: Group with peers; pair-bond; obtain sexual privacy.	REPRODUCTION, CHILD CARE: Nesting/nurturing: symbiosis; socialization.	MIDDLE LIFE: Care of aging parents; re-emphasis on worldly affairs; redefine indentity.	AGING MATURITY: Maintain identity, contact, health; accent care by others, mortality.

THE TOTAL SET OF BEHAVIORALLY DEFINED ARCHETYPAL PLACES

TASKS	
1 SHELTER	Elemental protection; protection for nesting activities; retreat from stimulation, aggression, threat, social contact; emotional recuperation.
2 SLEEP	Neurophysiological processes; recuperation, rest; reduced stimulation; labor and birth, postnatal care of mother and child; death.
3 MATE	Courting rituals; pair-bonding; copulation; affectionate behavior; communication.
4 GROOM	Washing; mutual grooming.
5 FEED	Eating, slaking thirst; communication; social gathering; feeding others.
6 EXCRETE	Excreting; territorial marking.
7 STORE	Hiding of food and other property; storage; hoarding.
8 TERRITORY	Spying; contemplation; meditating; planning; waiting; territorial sentry; defending; observing.
9 PLAY	Motor satisfactions; role testing; rule breaking; fantasy, exercise; creation; discovery; dominance testing; synthesis.
10 ROUTE	Perimeter checking; territorial confirmation; motor satisfactions; social and community control.
11 MEET	Communication; dominance testing; governing; education, worship socialization; meditation; cosmic awe; moral concerns.
12 COMPETE	Agonistic ritual; dominance testing; ecological competition; inter-species defense; intra-species defense and aggression; mating; chauvinistic conflict.
13 WORK	Hunting; gathering; earning; building; making.

A 1 Protection from elemental extremes; explore dwelling. A:2 Recognize bed; learn daily rhythms. A:3 XX A:4 Lose fear of wet face, sudden temperature change; regular grooming as primary contact ritual. A:5 Regulate feeding satisfactions. A:6 Discover excretion as separate from self; associate with setting and time. A:7 Acquire confidence in food abundance. A:8 Identify bed as primary secure place. A:9 Explore close environment; develop manipulative, cognitive skills. A:10 Route connects parts of shelter structures, provides orientation & change; motor satisfaction. A:11 XX A:12 Master frustration in competition w/siblings for attention & toys. A:13 (See A:9).

B 1 Differentiate subsettings; retreat from overstimulation, threat; emotional recuperation. B:2 Associate bed w/fatigue; learn volitional control of sleep; illness and recuperation. B:3 XX B:4 Learn to bathe, dress oneself. B:5 Coordinate feeding tools; communication; differentiate food from symbiotic source in mother. B:6 Autonomously control excretion. B:7 Learn to prepare food. B:8 Establish play "turfs"; orient to neighborhood; play protect territory from lookout; plan, wait. B:9 Role modeling; interact w/peers; fantasy, exercise, exorcism, creation, discovery, dominance testing. B:10 Enlarge route maps; differentiate settings, provide social encounters; learn safe wandering limits. B:11 Regular play/meeting rituals & places; elaborate functions; dominance testing. B:12 Games; fight; agonistic ritual; dominance testing. B:13 Acquire intellectual, motor skills.

C 1 Find alternate private shelter: auto, attic, stairwell. C:2 XX C:3 Meet w/opposite sex in private, public settings; obtain sexual privacy anywhere: autos, barns, etc. C:4 Groom for mating encounters. C:5 Communicate w/peers over food & drink. C:6 Privacy in excretion. C:7 XX C:8 Expand territory into intellectual domains, job. C:9 Learn autonomous hobbies. C:10 Provides social contact w/opposite sex. C:11 Meet w/peers, both sexes; establish new rituals. C:12 Sexual display: cars, sports, clothes (see C:3). C:13 Refine work skills.

D 1 Find new shelter. D:2 Share bed w/mate. D:3 Select mate; achieve couple privacy. D:4 XX D:5 Share food w/mate; increase food abundance. D:6 XX D:7 Enlarge larder for family. D:8 Expand territory to include mate. D:9 (see D:12). D:10 Maintain community of contacts. D:11 Meet w/couples. D:12 Personal display; ecological, mating competition. D:13 Apply skills toward life support.

E 1 Expand shelter for offspring (see E:5). E:2 Maintain sexual privacy against invasion by new young family. E:3 XX E.4 XX E:5 Increase abundance; feed family; gather, communicate w/family. E:6 XX E:7 Increase capacity & variety of food. E:8 Expand territory to include young & check frequently. E.9 XX E:10 XX E:11 Expand functions, contacts; governing, educating, mystical awe. E:12 Display in common values; conspicuous consumption. E:13 Improve capacities, performance.

F 1 Shelter contracts as young leave. F:2 through F:7 XX F:8 Territorial needs contract as young leave shelter. F:9 through F:13 XX

G 1 Maintain location or adjust to imposed change; adapt surroundings to needs. G:2 More time in bed, sleep less; possible confinement, compression of world to bedside. G.3 Adjust sexuality to changing libido; possible illness or loss of mate (see G 2). G:4 Possible inability to care for self. G:5 Arrange special diet; reduction of taste, smell spectra. G:6 Possibly require aid and equipment; lowered mobility may reduce functional dependability. G:7 Possibly require assistance gathering & preparing food. G:8 Passive observation of archetypal activities performed by others. G:9 New leisure activities to fit changing capacities. G:10 Reduction in home range scale; fear of exposure to attack. G:11 Need for contact w/& support from peers. G:12 Probable withdrawal from competition/defeat by young; defensive, evasive postures. G:13 Less active roles w/in former context; fend off retirement.

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