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## Harvard University

Supportive Living Environments for the Developmentally Disabled

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I am grateful for all the knowledge and insights that the Wizanskys have shared with me over the years. Our work together, as well as the families involved in that work, has truly enriched my life.

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## **Abstract**

Hundreds of thousands of adult Americans are able to work or attend education/training programs despite their physical or mental disabilities. For these people, a supportive living environment can provide the opportunity to live independently but with the structure and support they need to make the most of their lives and to participate in the community. This paper outlines a proven approach to meeting their needs for housing which provides a supportive living environment. After describing the basic prototype, it reviews each step of the process: evaluating prospective residents, locating and improving the property, financial considerations, zoning matters, neighborhood relations, organizational structure, program operations and transition of the residents.

## **Supportive Living Environments for the Developmentally Disabled**

by

Robert Schafer

Karen is 35 years old. Although born with certain developmental disabilities, she has completed her education, obtained a job that she enjoys very much and made her way in the world with the support of her parents, her brothers and sisters, and her extended family. Throughout this process she lived with her parents. After her mother died, she continued to live with her father in the house where she grew up. When her father died recently, her brothers and sisters needed to find an arrangement for Karen to continue to live in the same general area and to pursue her life interests. None of her brothers and sisters live in the metropolitan area where Karen lives. Karen very much wants an independent living environment, to live in a home that is hers, in a supportive environment in which she will continue to grow, but also in which she will have opportunities for privacy and independence. Her brothers and sisters want to find a living environment that will provide suitable support at a location that permits Karen to go to her current workplace by public transportation as she has done in the past. They also hope that the living environment will encourage and permit Karen to continue to grow and develop as a person and to make new friends. They want Karen to have a home.

Karen and her family are an example of the many families and persons who are striving for an independent living environment with the support that will permit its residents to grow and develop as individuals and members of the community. Although Karen and others similar to her have limitations on the things they can do, they have the skills and the willpower to live independently in a properly supportive environment. They seek a living arrangement that is structured in a self-perpetuating fashion, designed to meet their needs and accompanied by a support program that enables them to make the most of their lives and to participate in their community.

Karen's situation illustrates a compelling need for a supportive living environment.<sup>1</sup> In this age of reduced government commitment to housing, it is important to create approaches that do not rely on governmental assistance. The housing approach outlined in this paper is an example of marshaling private resources to serve a clear and present housing need. Although the approach does not require governmental financial assistance, it can be used in conjunction with assistance such as section 8 vouchers or certificates. In addition, many of the residents receive assistance from the Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) programs, forms of governmental assistance that are not linked to housing production.<sup>2</sup> It is hoped that the process described in this paper will encourage others to follow this path and provide sorely needed supportive living environments.

How large is the population that would be served by supportive independent living environments? The 1990 Census gathered information on persons with a work disability, a mobility limitation or a self-care limitation.<sup>3</sup> According to the 1990 Census, 10.4 percent of the civilian non-institutional population aged 16 to 64 (16,407,688 persons) have at least one of these disabilities.<sup>4</sup> However, many of these are gainfully employed at full time year round jobs or are living with a spouse. There are 3,804,863 persons with a mobility or self-care limitation who are not living with a spouse; 812,214 of them live alone; 137,534 live in group quarters, and the remainder apparently live with a relative (other than a spouse) or some other person.

The Americans With Disabilities Act of 1990 ("ADA") has increased the demand for information on the disabled population.<sup>5</sup> The ADA defines disability as "a physical or mental impairment that substantially limits one or more of the major life activities". As a result, the Census Bureau has added questions on the disabled to its Survey of Income and Program Participation ("SIPP"). The SIPP responses for 1991-92 find 9.9 percent of the entire population, or 24,117,000 persons, with a severe disability.<sup>6</sup> Severe disability is defined as (i) using a wheelchair or other special aid for six or more months, (ii) unable to perform one or

more functional activities or needed assistance with an activity of daily living, (iii) unable to work at a job or do housework, or (iv) having a selected condition such as autism, cerebral palsy, Alzheimer's disease, senility, dementia or mental retardation.<sup>7</sup> Most relevant to the topic of this paper, but by no means a complete statement of the demand for the type of housing discussed in this paper, is the finding that 6,789,000 persons fifteen years old or older, or 3.5 percent of the population, suffered with a mental or emotional disability, with 1,224,000 of them suffering from mental retardation. An additional 529,000 persons under the age of fifteen had a severe disability. These figures show that a substantial demand for supportive independent living environments should exist. Experience in developing these environments in Massachusetts confirms this demand. All the developments have been filled by the opening day.

Supportive independent living environments for people like Karen have been successfully created over the last 15 years.<sup>8</sup> The residents have mild learning disabilities ranging from the learning disabled, mentally retarded, autism, traumatic brain injuries, Down's syndrome, cerebral palsy, and minimal brain damage from birth. In all cases, their disabilities are mild and permit them to be involved actively in their neighborhood and community through work and other activities.

Creating supportive living environments cannot be pursued as a straight forward real estate development activity. The challenge in successfully developing this type of housing is in the management of the interpersonal relationships between the residents and their families. Additional time and effort must be devoted to managing the process. One consequence is that the process takes longer than the purely real estate portion of the activity suggests by itself. It is essential that the elements of real estate development be combined with the skills of social workers trained in dealing with persons with developmental and physical disabilities. The development of supportive living environments is a process that involves the selection of residents who are appropriate for the environment, and which involves those residents and their families in the development process. Because you are building a home as

well as a house, social workers are an essential ingredient in making this process effective and successful. It is their skills in selecting appropriate residents and working with the residents and the families in combination with the real estate skills of structuring, development and construction that makes this process successful and rewarding to the residents, their families and everyone who participates in it.

### **The Basic Model**

The model is a large single-family home of ten residents such as Karen, with common facilities such as kitchen, dining room and living room plus living areas for resident staff. Each resident has his/her private bedroom. The house also contains a small office area for staff to meet with residents and perform their functions. Typically, the home would include two living areas for resident staff. The physical structure must be large enough to accommodate ten resident bedrooms, three to four bathrooms for residents, one half-bathroom on the first floor for guests, kitchen, dining room, living room, staff office, and two two-room resident staff living areas including private bathrooms and kitchenettes in each of these resident staff areas. This translates into an approximately 25-room structure with approximately 6,500 square feet of space. Usually, it has been possible to locate a large, old, Victorian, single-family house or a sizable two-family house that can be modified to accommodate a single-family home for the residents. Some but not all of the houses are handicapped-accessible. While the houses developed over the last fifteen years range in size from six residents to twelve residents, the best size is a ten-resident home. Larger houses do not function as effectively. A minimum critical size is required to create the proper environment. Smaller homes, although they can operate effectively, increase the average costs for the families.

From an ownership and management perspective, the home is organized as a condominium. The condominium consists of ten bedrooms, and each family purchases one of these bedrooms. The common areas of the condominium are the entire remainder of the

property, including the kitchen, the living room, dining room, resident staff areas, bathrooms and staff office. On occasion, some of the individual bedrooms may have, because of the configuration of the house, a half-bath or a full bathroom. As a condominium, the house provides a mechanism for the self-perpetuating provision of a living unit and support services.

Experienced staff at each home are available to provide supervision and consultation on a wide variety of topics, including scheduling, planning, shopping, meal preparation, budgeting, use of leisure time, personal grooming and household maintenance. In addition, one or two resident staff persons live in the home to provide services on an on-call basis in the evenings, in the early mornings and on weekends. Since the residents are typically at work, at school or in training programs during the day, little staff is required from mid-morning to mid-afternoon.

Residents have the freedom to engage in activities on their own or in small groups with other residents or other friends. These are activities of their own choosing. Through living together in a shared environment that also includes private spaces of their own, the residents learn to respect individual differences and the interests of others. The goal is to develop a living environment and build a community of peers that support, care about and give affirmation to each other.

David and Margot Wizansky have described the mission to be one of assisting "individuals with disabilities to lead rich and full lives as productive members of the community."<sup>9</sup> They have identified four elements of this mission: contribution, connection, celebration, and community. Contribution involves the residents finding ways to contribute to society through work, community activities, volunteer activities, and helping others. Connection refers to making positive connections with others that are meaningful, mutually supportive, and life-enriching. Celebration involves the residents in recognizing and celebrating their accomplishments and the achievements of their friends. Community involves the participation in the community of their peers, in particular their home, and the encouragement of participation in the larger community, the neighborhood, and beyond.

A supportive living environment for persons with disabilities is one in which all people are treated as equal and worthy of respect, and encouraged to live lives that are full and complete in every sense. The residents grow through accepting themselves and knowing their own strengths and capabilities. By living independently, they become role models for other people with disabilities and demonstrate graphically to all people the ways in which we are all alike. The living environment must provide an opportunity for the residents to grow in self esteem and in their identity as adults, capable of and actively involved in managing their own lives.

### **Evaluation of Prospective Residents**

People with disabilities have a wide variety of capabilities and strengths. The variance of these strengths and capabilities within any single house must be within reasonable bounds so that the residents as a group can grow together and thrive as a family. In order to identify a qualified group of residents, experienced personnel, usually social workers, carefully screen prospective residents and their families prior to their participation. It is also important that the participating families understand the nature of the commitment they are making, both in time and money.

The evaluation process involves gathering information about each prospective resident, including the nature and duration of their major illnesses, as well as their current medications. In addition, it involves meetings with teachers, counselors, supervisors and other persons knowledgeable about the prospective resident. These may include the resident's psychiatrist, psychologist, social worker and physician. Naturally, the families must give permission for these contacts and the disclosure of the information necessary to make an appropriate and complete evaluation.

In general, resident criteria fall into four major areas: age, social skills, basic life skills, and physical capabilities. Generally, young adults between the ages of 18 and 40 are the target population. Social skills are critical, in the sense that they indicate how the resident



will relate to other residents and other adults. Living in a home with nine others and working with resident and non-resident staff requires a certain minimal level of social skills. In general, persons that exhibit grossly inappropriate behavior or have limiting emotional disorders are not appropriate for this living environment. Residents must be able to accept limits and rules. The program generally involves the residents in the establishment of the rules and regulations under which the house operates. They must respect the property of others and respond appropriately when spoken to. In general, they must be alert, interested, and motivated.

Basic life skills involve the practice of personal hygiene even if reminders are a necessary part of carrying out that practice, minimal ability to read and participate in money management, at least being able to make change in small denominations. They must also be capable of travel in the community; it is acceptable if they need training on the paths of travel and the use of systems and modes of travel. They must be able to learn these modes and paths of travel and to grow to use them on their own. They must have some skills that will allow them to be involved productively during the day.

Physical capabilities means that these homes would not be appropriate to persons who are subject to seizures that cannot be controlled by medication, or to persons who have their daily behavior impaired by medication. In addition, the houses are not generally barrier-free, and therefore the person must be able to negotiate stairs. Some of the houses have limited accessibility. For example, on occasion a house has been constructed so that the first floor is accessible and one or two resident bedrooms have been located on that floor. However, in these cases the upper floors of the house are not accessible to the residents that require barrier-free movement.

The determination of whether a resident is an appropriate candidate for these independent living environments involves a great deal of judgment and can only be made by caring and understanding professionals who work with and are familiar with the strengths and capabilities of this population. The prospective residents are identified by the social workers

through a network of relationships in the community of persons with disabilities or those serving persons with disabilities.

### **Locating and Improving the Property**

In general, four or five prospective residents and their families have been identified when the search for an appropriate property is commenced. The involvement of the families in the search for and selection of a property is an important part of the entire process, playing a role in bonding the participants together and making all participants comfortable with the selection that is made. This is not to say that the process cannot be an effective and positive one if the house has been selected before any of the potential residents. Such a situation is clearly appropriate when a house in an appropriate location becomes available at a particularly attractive price or circumstance.

The property must satisfy three basic requirements. First, it must be large enough to accommodate the proposed use. As we have discussed above, this involves a building that has approximately 25 rooms and the adaptability to provide sufficient bathrooms. Second, the property must be located on or near public transportation because the residents do not typically have access to an automobile as a mode of travel. Residents typically go to work or job training sites by public transportation and use public transportation for shopping and entertainment. If public transportation is unavailable, the capital budget must include a van and the operating budget must include the operating expenses of the van including payroll for the driver. Third, the property must be located in a neighborhood with a reasonable amount of activity that the residents can use as a local community resource and destination. The neighborhood should have shops, restaurants, and an entertainment facility such as a cinema.

Typically, the houses require a significant amount of capital expenditure, including upgrading the electrical system, adding new bathrooms and renovating all existing bathrooms, installing new kitchens (including kitchenettes in the resident staff areas), relocating and

adding internal walls, fire alarm system and sprinkler system. Frequently, the roof needs replacement and insulation has to be added to the walls and the roof. In addition, the exterior of the property is refinished. The result should be a physical structure of which the residents and the neighbors are proud.

The general philosophy is to use carpeting throughout the house in the common rooms and in all the bedrooms, with the exception of the kitchens which receive resilient flooring, resident staff area bathrooms which receive resilient flooring, and the residents' bathrooms which receive tile floors set in a mud base with a floor drain and sometimes with a rubber membrane. In addition, the walls in the residents' bathrooms are painted with deck paint and vinyl coated sheet rock ceiling panels are installed in the residents' bathroom ceilings using aluminum supports. The special treatment for the residents' bathrooms is a reflection of movement up the learning curve; overflowing water is a common maintenance issue.

Some of these improvements, such as the sprinkler and the fire alarm system, may not be required by local codes. However, they are well worth the expenditure as additional safety devices that provide additional comfort and satisfaction to the residents' families.

### **Financial Considerations**

Capital costs fall into seven general categories: acquisition, construction, furnishings of common areas, financing, development, carrying costs, and miscellaneous. Acquisition costs vary with the local real estate market and with the supply of suitably sized structures. Construction costs depend on the needed improvements and renovations. Financing and carrying costs depend on the duration of construction. The remaining items have less variability.

In the Boston area, acquisition costs including closing costs have been around \$350,000. Construction costs are in the \$50 to \$60 per square foot range. Total project costs are likely to be between \$830,000 and \$920,000. Table 1 is a summary of the capital costs of two typical homes based on actual experience in 1991 and 1996. The difference in the total

project costs for these two examples is equivalent to an annual adjustment of less than three percent. The typical cost of a unit is currently around \$90,000 in the Boston area.

Operating costs include the expenses of operating the real estate (insurance, real estate taxes, maintenance, reserves), food and household supplies and program support services. A reasonable estimate for these costs is approximately \$1,300 per month per unit. Finance or opportunity costs on the invested capital are not included in these figures. If the financing/opportunity cost on the invested capital of \$90,000 per unit is 10% per annum, the total monthly cost would be around \$2,050 per unit, or \$24,600 per year. The annualized cost compares favorably with other competing alternatives that are more expensive, provide less independence and opportunity to grow, and lack the long term nature of this arrangement.

One unusual feature of these houses from a real estate development point of view is that under proper circumstances the capital costs and operating costs of these houses may be deducted by the families as a medical expense on their federal income tax returns.<sup>10</sup>

### **Zoning Matters**

Residents and staff live together as one large family operating as a single non-profit housekeeping unit. A logical and important question is how the arrangement is viewed under the local zoning ordinances. Generally, zoning ordinances delineate uses into various categories such as single-family, two-family, apartment and so forth. In some situations they may have specialized categories of use. For example, there may be a provision for a licensed lodging house or for a group residence. Sometimes these specialized use areas have particular restrictions attached to them. For example, a group residence frequently refers to one that is licensed or operated by state government. The homes are not licensed or operated by state or local government, and as such would not qualify for such a specialized use category.

If a particular house does comply with a provision of the local zoning ordinance, it is constructed in accordance with that category. For example, at least two of the homes

involved buildings that had been licensed lodging houses. In these cases, that category was continued into the new use.

Federal law strongly assists the development of these homes. The United States Fair Housing Act was amended in 1988 to add specific protections for housing choices available to handicapped individuals. These amendments, among other things, make it unlawful to "discriminate against any person ... in the provision of services or facilities in connection with such dwelling because of a handicap of (A) that person or (B) a person residing in or intending to reside in that dwelling ... or (C) any person associated with that person."<sup>11</sup> The Act defines discrimination as including "a refusal to make reasonable accommodations in rules, policies, practices, or services, when such accommodations may be necessary to afford such person equal opportunity to use and enjoy a dwelling."<sup>12</sup>

Typically, zoning ordinances contain a definition of family. One example is that a family "means an individual or two or more persons related by genetics, adoption, or marriage, or a group of five or fewer persons who are not related by genetics, adoption, or marriage."<sup>13</sup> What do the Fair Housing Act amendments say about such a provision?

This definition of family means that a genetically related group of persons would be treated as a single family regardless of the number of persons in it. However, a group of unrelated handicapped individuals could only meet the definition of family if it was not larger than five persons. The definition of family has a differential impact on a group of persons that are related genetically or by marriage than on a group of persons who are not related genetically or by marriage but wish to live together as a single family. Such a distinction is completely permissible unless it involves a limitation on a protected group. Handicapped persons are clearly a protected group. All residents of our houses are handicapped persons within the definition of the Fair Housing Act.

Such a definition of family is a violation of the Fair Housing Act because the city or town adopted a rule, the definition of family, which is not a "reasonable accommodation" permitting occupancy of a house by a group of handicapped individuals.

The legislative history of the 1988 amendments to the Fair Housing Act demonstrates that Congress intended the amendments to invalidate zoning ordinances, practices and decisions that exclude persons with disabilities from communities of their own choice. In particular, the legislative history includes the following statement:

The Act is intended to prohibit the application of special requirements through land use regulations, restrictive covenants, and conditional or special use permits that have the effect of limiting the ability of such individuals to live in the residence of their choice in the community.<sup>14</sup>

The interpretation of the Fair Housing Act provisions on discrimination against handicapped persons and zoning ordinances containing definitions of family has been addressed by the United States Supreme Court. In City of Edmonds v. Oxford House, Inc., et al., the Supreme Court found that the definition of family that we have used as an example was not exempt from the Fair Housing Act requirement that the municipality make reasonable accommodation for handicapped persons.<sup>15</sup> In that case, the City of Edmonds argued that the definition of family was exempt from this requirement because it fell under another provision of the Fair Housing Act permitting the establishment of a maximum number of occupants per dwelling unit. The Supreme Court decided that this was not the case. In doing so, the Supreme Court made it clear that the definition of family did not establish a maximum number of persons per dwelling unit. Although the definition established such a maximum number for families composed of entirely unrelated persons, it had no such maximum for any other type of family falling within the definition. The Supreme Court stated:

Had the City defined a family solely by biological and legal links, [the occupancy exemption provision of the Fair Housing Act] would not have been the ground on which [the City of] Edmonds staked its case.... It is curious reasoning indeed that converts a family values preserver into a maximum occupancy restriction once a town adds to a related person's prescription 'and also two unrelated persons.'<sup>16</sup>

After the Edmonds case, it appears clear that a definition of family containing a limitation on the number of unrelated persons cannot be used to prevent a group of handicapped persons from living together in a single-family home in a single-family residential district. Lower courts have made findings consistent with this result.<sup>17</sup> In one case, the Federal District Court for the Eastern District of New York found that the town's limit of four unrelated persons was a failure by the town to make a reasonable accommodation as required by the Fair Housing Act, and was therefore discriminatory in violation of the Fair Housing Act.

What is the appropriate procedural route for a city or town to recognize and make a reasonable accommodation when it has a definition of family in its zoning ordinance containing a limitation on the number of unrelated persons? One approach would be to recognize the requirement to make such accommodation in the administration of the zoning bylaw. Another would be to seek a variance from this requirement of the zoning ordinance. However, the variance route is problematic because in some states, such as Massachusetts, a variance requires that certain specific statutory requirements be met. In Massachusetts, one of these requirements involves unique soil conditions, shape, or topography of the land or structure.<sup>18</sup> It is unlikely that the variation of the zoning bylaw from the number of unrelated persons could be justified on the basis of the unique soil conditions, shape or topography of a piece of land. In that case, an aggrieved party could challenge the variance and defeat the variance. The town would still be required to make a reasonable accommodation from its definition of family for unrelated handicapped persons living together as a family. In this regard, it would be more appropriate for the town to make its reasonable accommodation through the administrative enforcement of the zoning ordinance. It has been our experience

that cities and towns are willing to make such adjustments administratively in their zoning bylaws.

In some situations, communities have modified their zoning bylaws to explicitly recognize the Fair Housing Act's requirements. In Massachusetts, the Attorney General has reviewed one community's zoning ordinance in light of the Fair Housing Act and concluded that its definition of family was impermissible.<sup>19</sup> In connection with this review, the Attorney General recommended several amendments to the community's zoning ordinance. The community responded by amending its zoning ordinance to include the following language:

Notwithstanding the definition in the preceding paragraph, a family shall be deemed to include four or more persons not within the second degree of kinship occupying a dwelling unit and living as a single, non-profit housekeeping unit, if said occupants are handicapped persons as defined in Title 8 of the Civil Rights Act of 1968, as amended by the "Fair Housing Amendments Act of 1988." Such unrelated individuals shall have the right to occupy a dwelling unit in the same manner and to the same extent as any family unit as defined in the first paragraph of this definition.<sup>20</sup>

The litigation that has evolved over the definition of family in zoning ordinances has arisen in contexts involving occupants of houses that are recovering drug addicts or alcoholics or other persons with severe problems. These types of homes engender serious community and neighborhood opposition.<sup>21</sup> Homes for persons with mild developmental disabilities, such as the houses that we are discussing, do not engender such opposition.

### **Neighborhood Relations**

The experience in Massachusetts is that these homes are warmly received and welcomed into their neighborhoods and communities. None of the occupants have serious



problems that raise fears in the minds of neighbors or community members. Good relations with the neighbors are an important and critical ingredient to a successful development.

It is important to meet with the neighbors and introduce the concept and plans for a house soon after acquiring the house and prior to applying for building permits or commencing work on the property. It is recommended that family members visit with the neighbors and explain who the residents will be and the plans for the property. The houses on the street and some of the adjacent streets should be divided among the family members who each visit two to four houses. Often it is not possible to have a personal visit with each neighbor. For this reason, a neighbor may host a neighborhood meeting at which some of the parents of residents and the development group, including the social workers, meet with neighbors and explain the proposed use, occupants and improvements planned for the property. On occasion, a letter has been distributed describing the plans for the home and inviting the neighbors to call to discuss any questions they have.

When the neighbors have had an opportunity to hear who the residents will be and what improvements are planned for the property, a warm reception has always followed. Young families with young children have frequently said that this is an important part of their children learning about the diversity of today's world and how to live with it. Nearly always there are neighbors who have friends or relatives with similar problems. There is always empathy for the concept and support for efforts to create the supportive living environment.

The capital improvements to the property are far more than would occur in its normal use. In one situation, an abandoned and derelict property was acquired. This property had a very prominent location in the community and had been derelict for roughly ten years. It was restored as a significant historic building including removal of all the exterior siding and replacement with new wood siding. This home is now a landmark in its neighborhood and a pleasing and positive addition to its surroundings. In fact, an adjacent vacant parcel of land was developed into a very expensive four-unit condominium after renovation of this property.

The houses add to the neighborhoods that they are in, not only in psychological and sociological terms, but in their contribution to positive property values.

### **Organizational Structure for the Homes' Operation**

The operations of the home are organized around a condominium. The condominium has a Unit Owners Association with a board of trustees elected by the unit owners. The board of trustees is charged with overseeing the operation of the real estate aspects of the property and with the operation of the support program and activities. In connection with the latter obligation, the trustees select a service provider, which in turn hires and supervises the day to day activities of the support staff. In general, the structure operates very similarly to the way a typical condominium organization does.

In general, the social workers that have worked on the development of the house have been retained to provide the ongoing support services. However, there is no obligation under any of the documents to do so. Rather, this is a reflection of the high regard that the families hold for these social workers. They now manage and provide support services for over 80 residents in eight houses, one of which is in Rhode Island and the remainder of which are in Massachusetts.

The organizational structure, however, is significantly different from a standard condominium in several important ways. Foremost among these is the recognition that the residents must satisfy certain requirements to be eligible for residency in the home. The most obvious is that the residents must have some disability. However, the nature and extent of their disability are critical elements in the success of the house. Therefore, the organizational structure must deal with the approval of new residents seeking to reside in the house, and with the issue of residents who have received approval but who no longer satisfy the requirements for continued occupancy. In general, these decisions are made by the board of trustees, relying on and working together with the service provider. In those occasions when

specialized advice is appropriate, the advice of experts such as medical doctors and psychiatrists are also sought.

The occupants must be disabled persons compatible with the proper function of the living environment, the suitable operation of the support program, and the well-being of all residents. In order to implement these requirements, restrictions are placed on the ability of unit owners to transfer their units without the trustees having given prior approval of the proposed occupant and the ability of the proposed unit owner to financially support the program and the proposed resident's occupancy. The trustees are also given the power to terminate an existing occupancy in those situations where continued occupancy threatens the tranquillity of the living environment or the program, or imposes serious risks, burdens, or hardships on other occupants of the house. In situations of voluntary and involuntary transfers, qualified residents and families have been easily located and satisfactory transfers have been completed on several occasions.

The goal of developing these homes is to make available a supportive independent living environment for disabled persons. No family should participate in one of these developments with the objective of profiting financially from the experience. Participation by the residents and their families is not an opportunity to make a profit. In the spirit of this philosophy, the documents contain a restriction on the maximum resale price that any family can receive on a transfer of its unit. In general, the restriction limits the price to a simple un compounded four percent annual increase, taking into account additional capital expenditures invested in the unit during that owner's period of ownership of that unit.

### **Program Operations**

The program in the house assumes that the residents are capable of self-care, at least with some supervision, prompting or monitoring, and are involved during the day at work, job training, school, or other activities outside of the house. Except for special circumstances, the house is not staffed in the mornings and early afternoons during weekdays. Each house has a

house manager who works with the residents' daily living skills, such as budgeting, personal hygiene, housekeeping, and socializing. Part-time, weekend and live-in staff are supervised by the house manager. The live-in staff are available for overnight emergencies and provide early morning supervision. The residents remain involved in the house operation through regular meetings with the house manager and others to make decisions about chores, staffing, household policy, celebrations and social activities and to assist each other with needs and problems.

Each house also has a clinical supervisor who supervises the house manager and who meets regularly with the residents as a group without the house manager or any other staff present. These meetings give the residents an opportunity to express their concerns, desires and needs, as well as to express their feelings about the staff. They also give the residents an opportunity to affect the operation of the house. The clinical supervisor also spends time in these group meetings addressing topics that are affecting the group at the time. Examples would be issues of separation, interpersonal relationships, appropriateness of various forms of behavior or other similar matters. The clinical supervisor also meets individually with residents as needed, and privately with the resident's family to discuss any issues.

### **Transition**

Establishing one of these houses and moving the residents into occupancy is a major transition point in the lives of the residents and their families. Typically, each family has been caring intensely for the resident throughout the resident's life. As a result, the families often have to navigate a passage through the experience of "letting go." This experience is analogous to the emotions and feelings generated when a son or daughter departs for college, an undeniable physical change along the path to independent living. The families worry about how their son or daughter will survive without their care. The following expresses the feelings of one parent.

Many years ago, we saw a poster with a bird ascending from a tree branch. The poster read, "There are only two things we can leave our children. One is roots, the other is wings." Because of our supportive family and religious traditions, my husband and I felt confident about providing roots for our children. However, we often felt puzzled about how to foster independence in our daughter with special needs, and how to "let go."

We worried about our daughter's future. How would she survive without our vigilant care? One evening when she was 21 years old, she announced, "I feel lonely and depressed at home and you keep telling me what to do." Since not leaving home represented another painfully missed milestone, we promptly sought an appropriate adult housing situation for our daughter.<sup>22</sup>

After their daughter had moved into one of these houses, this parent was able to say that "we have given our daughter roots and wings."

The residents are also going through a significant transition in their lives. They're wondering about the provision of meals, about how to interact on a day to day basis with new friends and residents, and whether there will be any rules.

The transition process begins with the process of selecting a house. The families meet together to discuss options and make plans. They participate in the selection of the specific piece of real estate. They participate in discussions over what modifications need to be made to that real estate and what steps have to be taken to acquire it, make the modifications, arrange for construction financing, hiring a contractor and supervising the construction. These regular meetings are an essential part of the process of bringing the families together to develop a new extended family consisting of these families as a group working together for a common objective of the well-being of all of the residents. This does not mean that everyone is always in agreement. However, it has been the experience that the members of this "extended family" grow to respect each other and devise a manner of proceeding, even when

some members are not in full agreement with other members. At times this involves deferring to the predominant view of the group as a whole.

While the families are meeting regularly, the residents also begin to meet regularly with the house manager. These meetings do not involve the parents or their siblings and serve to foster the residents' sense of independence, as well as the beginnings of a transition recognizing their separateness from their family. It is in these meetings that the residents begin to discuss their concerns about meals and rules and interaction with each other. They participate in developing the community that they will be living in, including the rules and the assignment of chores and responsibilities for the operation of the house.

One topic that always comes up in the parents' meetings is how will the units be distributed? The answer is that parents as a group will decide on a procedure for distributing the units when the units have been renovated and can be seen by all the participants. In general, the group of families decide on some form of lottery, and families select units in the order established by that lottery. However, the families have taken into account specific needs and desires of other families, especially where there is a need for physical access that requires a particular resident to be located on the first floor of a house. Experience has shown that the bedroom unit of each resident is less significant than the parents anticipate at the outset. The residents spend much of their time in the common areas of the house, and the personal space of their bedroom is less important than their parents originally contemplated. In addition, each resident becomes quite attached to their particular bedroom. In fact, they become so attached that when given the opportunity to relocate to other more spacious or otherwise seemingly more preferable bedrooms within the house, they decline the opportunity.

An example of another parent's reaction to the opportunity for their son to live independently follows:

It began with a phone call to us from David Wizansky asking if we'd be interested in purchasing a house for our son Mark and others. After a long conversation and before hanging up, I remember asking him if he'd be sure to call back. It was like a messenger from another planet who had arrived on earth to solve your earthly problems and who might disappear before you realized what happened.<sup>23</sup>

When the house is operating, the residents continue to meet regularly on decisions or changes to household policies and operations. The families continue to be involved in regular meetings through the board of trustees, although it is fair to say that the residents' involvement grows in intensity with time, and the involvement of the families declines. This illustrates the success of the program. It shows the individuals growing to accept themselves and to learn their strengths and capabilities. It shows their adaptation to independent living and their maturity. While residents visit home relatively frequently after they first move into these houses, it is not uncommon for these visits to become relatively infrequent after a period of time. This reflects the transition from the visit home being a decision of the parents to the decision being that of the residents, as it is with any other young adult.

As David and Margot Wizansky have said:

Our success is measured by the growth in self esteem of the individuals we work with and their growing identity as adults capable of and actively involved with managing their own lives.<sup>24</sup>

There is no greater reward than to see the joy and pleasure in the faces of these young men and women as they navigate this course to independent living, and in the faces of their parents and siblings as they watch their sons, daughters, brothers, and sisters grow and develop in ways that many of them had only dreamed about.

**Table 1**

**Illustrative Capital Costs**

	<b>Year Acquired</b>	
	<b>1991</b>	<b>1996</b>
<b>Acquisition</b>	\$328,000	\$350,000
<b>Construction</b>	322,000	375,000
<b>Common Area Furnishings</b> (appliances, furniture, set-up)	25,000	20,000
<b>Financing</b> (points, interest, lender's legal)	32,000	42,000
<b>Development</b>	90,000	80,000
<b>Carrying Costs</b>		
<b>Insurance</b>	5,700	9,000
<b>Real Estate taxes</b>	3,600	6,000
<b>Heat &amp; Utilities</b>	2,700	4,000
<b>Architectural/Surveying</b>	10,000	10,000
<b>Unit Closings</b>	5,000	5,000
<b>Miscellaneous</b>	3,500	1,000
<b>TOTAL</b>	\$832,500	\$905,000



## Endnotes

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- <sup>1</sup> See Diane Griffiths, “Waiting in the Wings,” (Waltham, MA: Family to Family, 1997).
- <sup>2</sup> For a description of the SSI and SSDI programs, see Linda L. Landry, An Advocate’s Guide to Surviving the SSI System (Boston, MA: Disability Law Center, Massachusetts Law Reform Institute, 1995).
- <sup>3</sup> The 1990 Census Questionnaire asked a sample of the population two questions. One question inquired whether the person had a physical, mental or other health condition that has lasted for six or more months and limited the kind or amount of work the person can do at a job (with a Yes/No response) or prevented the person from working at a job (separate Yes/No response). The other question asked the person whether a health condition that has lasted six or more months causes the person any difficulty “going outside the home alone , for example to shop or visit a doctor’s office” (with a Yes/No response) or causes the person any difficulty “taking care of his or her own personal needs, such as bathing, dressing or getting around inside the home” (a separate Yes/No response). The 1970 Census only gathered information on work disability. The 1980 Census only gathered information on work disability and ability to use public transportation.
- <sup>4</sup> U.S. Census Bureau; “Disability 1990 Census, Table 1. U.S. Totals:” Revised October 18, 1996; <<http://www.census.gov/hhes/www/disable/census/tables/tab1us.html>>.
- <sup>5</sup> Public Law 101-336; 42 U.S.C. §§ 12111 et al.
- <sup>6</sup> U.S. Census Bureau; “Disability Status of Persons (SIPP), Table 1. Number and Percent of Persons By Sex and Type of Disability: 1991-92;” Revised October 30, 1996; <<http://www.census.gov/hhes/www/disable/sipp/disstat.html>>.
- <sup>7</sup> SIPP has included questions on limitations on (a) functional activities (seeing, hearing, speaking, lifting and carrying, using stairs, and walking), (b) ADL’s or activities of daily living (getting around inside the home, getting in or out of a bed or chair, bathing, dressing, eating or toileting), and (c) IADL’s or instrumental activities of daily living (going outside the home, keeping track of money or bills, preparing meals, doing light housework, and using the telephone). SIPP also has information on the use of a wheelchair, canes, crutches or walkers; presence of certain condition related to mental functioning (mental or emotional disability such as autism, cerebral palsy, Alzheimer’s disease, senility, dementia, or mental retardation); presence of a work disability, and disability status of children. U.S. Census Bureau, “Statistical Brief: Americans With Disabilities;” Issued January 1994 (printed from the Census Bureau’s Internet site on June 25, 1997).

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- <sup>8</sup> The housing environment described in this paper was developed by David and Margot Wizansky, social workers, Hendrik Holmes, architect/developer, and Robert Schafer, attorney/developer, in 1982. The Wizanskis are the principals in Specialized Housing, Incorporated which provides support services to these houses and other living environments for the disabled. The Wizanskis and Schafer are principals in Supportive Housing Solutions, Inc. which develops housing for the disabled.
- <sup>9</sup> Specialized Housing Incorporated, “Mission and Philosophy” (undated).
- <sup>10</sup> For more information on this deduction and other deductions available to parents of persons with developmental disabilities, please see the 1994 Income Tax Guide prepared by The Arc Michigan, or a more recent edition of this pamphlet. See also, James N. Calvin, “Housing for the Developmentally Disabled and the Medical Expense Deduction.” The Tax Advisor ( March 1989).
- <sup>11</sup> 42 USC §3604(f)(2) (19 ).
- <sup>12</sup> 42 USC §3604(f)(3)(B) (19 ).
- <sup>13</sup> This is the definition of family from the City of Edmonds, Washington zoning ordinance. See City of Edmonds v. Oxford House, Inc., 115 Supreme Court Reporter 1776, 1779 (1995).
- <sup>14</sup> H.R. Rep. No. 711, 100th Cong., second Sess. 22, at 24 (1988).
- <sup>15</sup> 115 Supreme Court Reporter 1776 (1995).
- <sup>16</sup> Id. At 1783.
- <sup>17</sup> See for example the result in Oxford House, Inc., v. Town of Babylon, 819 F.Supp. 1179 (E.D.N.Y. 1993).
- <sup>18</sup> Massachusetts General Laws, Chapter 40A, §10 (199 ).
- <sup>19</sup> See letter dated April 20, 1989, from the Attorney General of the Commonwealth of Massachusetts to the City Manager of Cambridge, Massachusetts.
- <sup>20</sup> City of Cambridge, Massachusetts, Zoning Ordinance (amendment adopted in 1989).
- <sup>21</sup> For an example of fierce opposition from the community, see Support Ministries for Persons with AIDS, Inc. v. Village of Waterford, 808 F. Supp. 120 (N.D.N.Y. 1992).
- <sup>22</sup> Barbara Richmond, parent, in Specialized Housing, Inc., Passport To Independent Living (1996).

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<sup>23</sup> Diane Asseo Griliches, “How We Came To Be,” Macril Messenger (December 1992).

<sup>24</sup> Specialized Housing Incorporated, “Mission and Philosophy” (undated).