



# **Exploring Alternative Models in Supported Living**

United Cerebral Palsy of MetroBoston

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## **EXPLORING ALTERNATIVE MODELS IN SUPPORTED LIVING**

### **ABSTRACT**

For thirteen years, United Cerebral Palsy of MetroBoston has delivered Supported Living Services to individuals with physical disabilities using a case management model. This model is based on the independent living philosophy which provides individuals with the greatest amount of control over their lives by encouraging them to direct their individualized case management/coordinator supports. Although many individuals have been supported through this model, serious flaws in this case management model of service delivery have emerged. Individuals with physical disabilities, their families and associated field professionals have reported a growing trend in potentially unsafe and unsatisfying living situations resulting in less than fulfilling lifestyles for many individuals with disabilities. United Cerebral Palsy of MetroBoston, in our commitment to provide services that meet the needs of individuals with disabilities, sought funding through this grant for the purpose of developing alternatives to the current model that will create increased options and opportunities for people with disabilities. Through the use of a questionnaire developed by project personnel, access to accessible, affordable, and safe housing, able-bodied supports, transportation, community membership, and opportunities for social outlets were all identified as areas significantly missing from the individuals surveyed. The results of this project address and support a systems change approach to providing residential supports to individuals with disabilities. Although contradictory to the current philosophical ideology of independent living, the general response of individuals surveyed supports the creation of alternative ways in which to provide housing for people with disabilities that better meets the social and physical needs currently lacking in the system.

### **UCP BACKGROUND INFORMATION**

**History:** United Cerebral Palsy Association of MetroBoston, Inc. has an extensive history in the provision of services to persons with cerebral palsy and other disabilities. The founding organization, The Cerebral Palsy Council of Boston, Inc. was established in 1950 by a group of concerned parents and professionals. In 1954, United Cerebral Palsy of the Metropolitan Area, Inc. was established and affiliated with National UCPA, which was founded in 1948. In the years to follow, the association's name was changed to UCPA of MetroBoston, Inc. (UCP). Since 1950 a variety of programs have been offered by UCP ranging from preschools to family support to supported living and employment programs serving all age groups. Our multi-program sites, located throughout the Boston area, reflect our commitment to the concept of community based services.

**Mission and Guiding Principles:** The mission statement of UCP mandates that the purpose of the agency is to advance the independence of individuals with disabilities. With this as a foundation, UCP has developed programs that strive to maximize the quality of life for its participants and allow them opportunities to live and work in normalized, integrated settings. UCP is committed to equip and enable individuals with cerebral palsy and other disabilities and their families to obtain the fullest possible participation in an integrated community, to support freedom of choice by assuring multiple options in daily living, and to empower individuals with disabilities in decision-making that effects their lives. All programs and projects undertaken by UCP focus on the improvement of the quality of life for persons with disabilities. The agency adheres to the value of respecting and acknowledging the right and responsibility of persons with disabilities to be active decision-makers in shaping their services.

**Qualifications to conduct project:** UCP is extremely qualified to conduct this project and to explore alternative models in supported living. This program model provides case management services to people with severe disabilities which enables them to live in their own homes and apartments. Often times, Personal Care Attendants are utilized to provide direct physical care for individuals. Individuals who enter the program are assessed to determine the number of case management hours that are required to meet their needs. Most individuals receive 5 – 10 hours of case management per week and gain assistance in the areas of money and medication management, personal care attendant management, and help scheduling appointments. The organization has operated a successful Support Living Program since 1987. The program has grown in number of people supported from 6 to 32 and approximately another 20 have moved on to total independence. Because of our long standing relationship with Massachusetts Rehabilitation Commission and the Department of Mental Retardation as one of the few providers of supported living services to people with physical disabilities, UCP feels qualified to explore other options with this population.

**Experience working with people with developmental disabilities:** UCP has an extensive history of working effectively with people who have developmental disabilities. The organization operates several community-based programs throughout the Greater Boston area including residential supports, family support, day habilitation, Personal Care Attendant Services, supported living, and a toy lending library for children with disabilities and the concerned adults in their lives. Annually, over 300 children and adults with disabilities and their families receive services and supports through our programs. UCP is committed to providing supports on an individualized basis, tailoring supports and services to the needs of each person. These services are designed to enhance the lives of people with disabilities to live more independently in the communities of their choice.

UCP currently supports 35 individuals in a variety of residential settings including a staffed apartment, a group home, a congregate living house, and numerous supported living apartments. As part of these programs, participants receive skills training and are assisted with a variety of areas that they are unable to manage on their own. UCP contracts with Massachusetts Rehabilitation Commission to provide supported living

services to individuals with disabilities in the Greater Boston and Northeast areas. In addition, a similar service has been provided to adults under contracts with the Department of Mental Retardation and Community Medical Alliance (an HMO working with individuals with severe and/or chronic disabilities). Individuals supported under these programs have included those with head injuries, developmental disabilities, cognitive, psychiatric, physical, and medical disabilities.

## **PROJECT INFORMATION**

**Purpose and need of project:** For many years, UCP has operated a Supported Living Program funded by the Massachusetts Rehabilitation Commission and the Department of Mental Retardation, as well as private insurance companies. This program provides case management services to individuals with physical disabilities so that they may reside in the living situation of their choice. The program provides supports to over 32 individuals throughout the Greater Boston Area and is mostly an effective, efficient method for allowing people to live in communities of their choice. Satisfaction results of individuals served are very high for those individuals who have the ability to truly appreciate the benefits of living independently.

However, for some individuals, the design of the program has not proven to be the most effective way of supporting them. Since individuals receive a pre-determined allotment of case management hours as the result of a needs assessment, services are not provided on a 24-hour, 7-day a week basis. When Personal Care Attendants are not present, many individuals are alone for several hours at a time. Many complain of isolation and loneliness. Weekends are very difficult, as opportunities for social outlets are limited. Often time, individuals rely on family members to provide them with social or recreational activities. Many families have voiced their concern that they do not wish to see their family member live in a group residential setting. They feel that other program models must be created so that staff is available on a continuous basis for support, safety, facilitation of recreational and social opportunities and emergency back-up in the event that PCAs do not report for their shifts.

For the purpose of this grant, UCP has explored the creation of other models of living arrangements that would benefit individuals with physical disabilities. While staff is committed to creating different opportunities for consumers, due to the demand of everyday job requirements, spending the time to create and develop alternatives is often not accomplished due to the time required to complete such projects. This project allowed for the hiring of a staff person for 20 hours a week over a 6-month period to work with consumers, family members, state agencies, and housing authorities to develop a plan for the creation of alternative models of support that could be implemented by UCP or other similar organizations.

**Innovative nature of the project:** The innovative nature of the outcome of this project will allow for the creation of new opportunities for people to be better served and live

more complete lives. It is our hope to create alternative models that are not currently being offered in Massachusetts.

## **PROJECT METHODOLOGY**

Following the hiring and identification of project personnel, a questionnaire was developed which guided the acquisition of information needed to create the proposed alternative model. Using input from consumers, family members, funding sources, and other providers who offer similar services, two questionnaires (one specific for consumers, one specific to family/caregivers) were developed and were piloted for validity to ensure clarity of questions and information sought.

To provide the project endeavor with diverse perspectives and field related expertise around perceived gaps in housing and supports for individuals with disabilities, careful attention was taken in the identification of participants to be surveyed. Participants were identified through established associations with consumers and their family members, support providers, state agencies as well as recommendations from a project mailing to supported living and field related professionals. To ensure the opportunity for full participation, all identified survey participants (individuals with disabilities, family members/caregivers, service providers/field related professionals) were interviewed at their convenience and with necessary accommodations to meet their individual physical and cognitive needs as well as their communication style. Once the interviews were completed, the data was reviewed and synthesized to track general trends and identify themes.

Through programmatic research and recommendations from interviewed housing professionals, several programs were identified and site visits were conducted by the project staff and interested individuals with disabilities and their family members. These site visits also provided for an opportunity to explore information on funding sources, funding problems, and benefits to the individuals supported.

The final phase in developing an alternative model of service delivery to encompass as many of the needs identified through the project involved a comprehensive research and look into the current housing market.

## **RESULTS**

Over a three-month survey period, twenty individuals with disabilities and twelve caregiver/family members were interviewed using the developed questionnaires. In addition, approximately fifteen associated field professionals were interviewed to further assess the need for housing alternatives for people with disabilities within Massachusetts. These field professionals included representatives from the Department of Mental

Retardation, Massachusetts Rehabilitation Commission, Independent Living Centers, providers from other supported living agencies, and medical and mental health professionals.

Of the twenty individuals with disabilities surveyed, 60% reported being between the ages of 25-40, 20% being between 18-25, and the remaining 20% of participants were older than 40. In response to the question of primary disability, seven reported having Cerebral Palsy; two with Spina Bifida; one with Muscular Dystrophy; three with a spinal cord injury; and two reporting "other" to the primary disability categories. In response to ethnicity, the majority identified themselves as Caucasian. Of these twenty participants, the majority reported living alone in a one-bedroom/one bathroom apartment in an elderly complex. The remaining participants reported living situations identified as low-income family housing and shared housing. Eighty-seven percent of the participants reported living in a subsidized unit and the average length of time lived in their current residence was four years.

In analyzing the results of both questionnaires utilized as well as information provided through interviews with field professionals, several themes emerged as not only areas of difficulty, but also as areas that significantly impact upon the individuals' quality of life. The themes identified include challenges around housing availability, accessibility, transportation, staffing supports with recurring themes of isolation and safety.

Also emerging from the results is the philosophical differences between these themes and the independent living ideology. A majority of the individuals and field professionals surveyed recognized that in response to the supports identified as missing, that individuals are asking for the option of a more integrated/assisted model of independent living. It was recognized, however, that this level of support, in part, defeats the independent living philosophy. Opinions offered were clarified as being personal and not necessarily reflective of an agency, program, or the disabilities rights movement. Despite this clash, it was expressed by many of these professionals that they would support creative and alternative ways of supporting individuals in the community.

### ***Availability of Housing***

Of the six identified themes, the availability of accessible housing was reported as having the most significant influence on the quality of lives for individuals with disabilities throughout Massachusetts. Questionnaire participants identified an average wait of up to two years for accessible, affordable housing and only one participant reported having a Section 8 voucher. However, this was not being used because of limited availability of accessible housing in which they could use their voucher. Also, many participants reported that, after their prolonged wait for housing, they had accepted a housing option that was not reflective of their interests and needs out of desperation and frustration. Some compromises in housing resulting from limited availability included location, size, and accessibility.

Many of the participants surveyed reported that although the location of a housing opportunity is an essential component to their well-being and safety, it is the most often

compromised because of limited housing availability. This was supported in the results as fifteen of the twenty participants reported not living in a location of their interest. The participants further reported that when considering location as a component of housing that an assessment is made not only of the building but also of the neighborhood and larger community. Special emphasis must be given to wheelchair accessibility, access to emergency personnel, access to local merchants, and the accessibility of public transportation.

### *Accessibility*

With most participants living in a single apartment, accessibility was another commonly identified factor contributing to the dissatisfaction many have with their current living situation. Seventy-four percent of questionnaire participants responded that they considered their apartments to be only moderately accessible when they moved in and still in need of further modifications at the time of the survey. Participants and field professionals both reported that further modifications to increase accessibility were limited due to the high cost of adaptive equipment and the lack of available funding for these adaptations. Also related to the accessibility of many participants' apartments was the size of equipment used to enhance accessibility. Over the years, due to advances in technology, the size of many adaptive equipment devices have grown and equipment, such as wheelchairs and transfer devices, were described as cumbersome and responsible for occupying what little space is often available in a one-bedroom apartment.

### *Transportation*

Participants and field professionals presented transportation as another area impacting the quality of life of individuals with disabilities living independently in the community. Although several public transportation options are available to individuals with disabilities throughout the state of Massachusetts, participants of the survey reported having significant problems with reliability, availability, and accessibility. All of the participants of the survey reported that transportation is not provided by their current housing facility, therefore increasing their dependence on and frustration with unreliable and often inaccessible means of transportation.

Another outcome of limited access to transportation is the contribution to a feeling of isolation often experienced by many individuals with disabilities. In this current market where accessible housing is so limited, isolation from peer groups and community is becoming the norm. Individuals with disabilities are forced by necessity into accepting available apartments or living situations that may not meet their needs and interests. Many participants identified living in elderly complexes where social opportunities with their peer group are naturally non-existent. Access to transportation is an essential component in the lives of individuals with disabilities so that they can have access to the social, vocational, and recreational opportunities that enhance most people's quality of life.

## *Staffing Supports*

Another theme identified in this project with serious implications on individuals' well-being and safety, involves the staffing supports necessary for individuals to live independently in the community. In Massachusetts, many adults with physical disabilities living in the current model utilize and depend on Medicaid's Personal Care Attendant (PCA) Program to meet their day to day essential life needs. This program is intended to be self-directed to enable individuals to live as independently as possible while maintaining the greatest amount of control over their needs. Consumers of the PCA program must be able to assume the responsibility for recruiting, hiring, training, scheduling, supervising, payroll functions, and terminating PCAs. Although this program's philosophy is well-respected within the field and by the consumers of this program, survey results indicate that PCA consumers are spending significant amounts of time, coupled with stress, in their efforts to manage the responsibilities of this program.

Throughout the survey, PCA consumers, their families, and field professionals reported significant concerns about the compromises made by many individuals in their standard of care. Because of significant difficulties in recruiting and maintaining qualified PCAs, many participants reported an unhealthy dependence upon PCAs coupled with the acceptance of a lower standard of care in order to maintain at least a minimum level of support necessary to continue living independently. As a result, there is increasing concerns among family members and field professionals for an individual's health, safety, and individual's ability to manage the responsibilities of this program. Because there are no alternatives or safety nets in the current model to meet the day to day essential life needs, there were overwhelmingly positive responses to the questions in the survey about the impact and benefits of having an able-bodied person available at all times.

Also related to participants struggling with the management of the PCA program was the identified impact of location on their success in the recruitment and hiring of staff (PCAs). Not unlike most, PCAs are attracted to employment opportunities that are safe and easily accessible.

Because of limited space common to many apartments, several participants presented concerns about the lack of adequate sleeping arrangements for their overnight staff. This results in issues of privacy and comfort for many consumers and their PCAs further detracting from the desirability of this position.

Specifically related to the stress associated with managing staffing supports were the profound responses of several individuals surveyed. At the time of the survey, two individuals (BG, MS) were struggling with the consideration of a nursing home placement as an alternative to continuing to live independently. This was due to the day to day stress associated with independently managing staffing supports to meet their essential life and personal care needs. They both reported that the compromise of giving up their independence was worth losing their ongoing fears and stress associated with managing a PCA program. Another individual surveyed (DB), who was hospitalized at

the time of the survey, stated that on more than one occasion she had been left in her bed, unattended to, for a period of 24 hours with the only safety net of calling 911. This woman was hospitalized after sustaining a severe injury when she attempted to transfer independently in the absence of her PCA. Because of this incident, she refused the option of returning to an independent living situation and was awaiting a potential placement in a community based group home. The stress of managing staffing was also identified as the primary reason for the institutionalization of another individual surveyed (KM). This individual, after several years of struggling to live in her own apartment, associated her difficulties with managing staffing as a reflection of her own inability. The stress of her own insecurities and dependence upon her family resulted in a psychiatric hospitalization where she remains awaiting an alternative to the current independent living model so that she can enjoy community living without the day to day stress of managing staffing. Another individual surveyed (SH) described having spent many holidays in the emergency room at a local hospital because she did not have staff to work and could not safely be left alone without anyone to care for her. Another response, which supported the survey results related to staffing supports, was the comment of a woman living at New Horizons Village. This woman was disabled as a result of a tragic accident and prior to moving into New Horizons Village, an assisted living program for people with disabilities, was living independently in an apartment with the assistance of a home health care type of support. She reported finding this level of support inadequate to meet her needs and difficult to coordinate around her personal care needs and stated that “by moving to an assisted living program where I share in the responsibility of managing staffing that I can now start living my life.”

### ***Isolation***

Because many of the individuals with disabilities surveyed have accepted housing that does not meet their needs and interests and transportation options are described as limited, issues with isolation are becoming more pronounced. According to the healthcare providers surveyed, issues with isolation are being attributed to the growing and inappropriate use of medical and mental health resources. Of the 20 participants surveyed, two were hospitalized at the time of the survey. As described by themselves and their families, the hospitalization resulted directly from the stress and isolation of independent living. Another individual surveyed (JD) reported experiencing regular bouts of depression compromised by his limited mobility and isolation from peers and supports. He is living in a predominantly elderly building with few opportunities for social activities or relationships with peers and desires an apartment with opportunities for social activities.

In response to survey questions about individuals' interest in recreational activities in their housing facility, fifteen responded that their facility had an accessible common space for activities, however, only seven of those participants reported having regular recreational opportunities available to them. Of those seven, six of the survey participants do not participate in the activities specifically because the activities are geared towards the interests of the elderly tenants. The most common reported activities of interest to the participants included educational opportunities, games, music, guest speakers, outings, arts and crafts, movies/shows, and support groups.

## *Safety*

As discussed in previous sections, concern for safety was a recurring theme throughout this survey. Individuals, family members, and field professionals reported concerns for safety related to housing, staffing, and transportation.

## **SUPPORTED LIVING PROGRAM VISITS**

The development of an alternative model of supported living was not only influenced by the information from the questionnaire results and interviews but also from valuable information provided by three scheduled supported living program visits. These three site visits were identified early in the project by recommendations made by consumers and field professionals.

The first program visited was United Cerebral Palsy of Rhode Island's Kara Estates. This program was developed several years ago as a result of a housing needs assessment for individuals with disabilities. Kara Estates is a moderately sized apartment complex in a suburb of Providence with 15 self-contained single and double occupancy units. All of the apartments were designed under the direction of wheelchair users and were described by the tenants as not only wheelchair accessible but well equipped with many innovative adaptations to further increase accessibility and safety.

In addition to the impressive physical dynamics of the complex is the well-established system of support for the tenants who are described as adults with physical disabilities with varying disabilities and cognitive functioning. Kara Estates is more than an affordable rental opportunity as it provides their tenants with a staffing component that addresses each person's personal care needs while providing for on-site supports for emergencies, socialization, and recreational opportunities. Unlike Massachusetts, Rhode Island residents with a physical disability who are eligible for personal care assistance appear to have greater flexibility in the use of their funding resources. Rhode Island residents can select an agency that offers programs that meet their interests and needs to be the recipient these funds. It is this flexibility that has led to the development of innovative and encompassing services that provide for many of the social and physical aspects of independent living currently missing in Massachusetts.

The next program visited was UCP of Eastern Connecticut's supported living program for adults with disabilities. This model, which is described as a supported living arrangement, was representative of the most integrated model of the three sites visited. This program was created in the early 1990's with great emphasis on individual choice, control, community inclusion, and safety. This program is innovative and distinct in that it is truly community based because it is operated in several large privately run apartment complexes. UCP of CT attributes their success in their service delivery to their broad-based staffing component which is operated within each apartment complex. The accessibility of 24-hour UCP staff offers to its consumers flexibility, spontaneity, safety,

and social opportunities. Each of UCP of CT's Supported Living Arrangements allows for the active involvement of consumers in the hiring decisions of all staff without the stress associated with maintaining sole responsibility for implementing staffing as seen in Massachusetts.

New Horizons Village was the third program visited. This program is best described as an assisted living program for individuals with disabilities. The philosophy and design of New Horizons was developed over a fifteen year period by a group of people with disabilities struggling with limited opportunities for independent and community living. New Horizons is a large complex of 100 single and double occupancy units available exclusively for adults with physical disabilities. Similar to Kara Estates, New Horizons was architecturally designed with great sensitivity to the needs of people in wheelchairs. Each unit is wheelchair accessible with features to enhance the safety and independence of their tenants.

New Horizons prides itself on its commitment to provide an umbrella of services for its tenants while maximizing individual control. Similar to Massachusetts, each resident of New Horizons is assessed annually for their level of need and then provided assistance from case management staff in the recruitment, hiring, training, and supervision of personal care attendants. In addition to case management supports, New Horizons provides for 24 hour staffing for needs that arise outside of regularly scheduled PCA supports.

Although New Horizons reports high level of satisfaction from its tenants and while the model of New Horizons addresses most of the concerns identified through UCP's survey, New Horizons has been criticized for being extremely isolated, segregated, and bearing features associated with institutions. Unlike many of the participants surveyed, New Horizons reported that there was a general disinterest in the shared living arrangements of two bedroom units. This is most likely due to the fact that needs for socialization were met through the total program design.

## **PROPOSED MODEL OF SUPPORTED LIVING**

In response to the themes that emerged throughout the research project, UCP proposes the following alternative housing model. Because of the philosophical clash clearly identified throughout this project, it is our opinion that this should be just one option in a continuum of services ranging from independent apartments to traditional group homes so that an individual can choose the model that best meets his or her unique needs.

Because UCP is committed to integration, the opinion of those involved in this project is that in Massachusetts the development of a fairly small apartment complex of eight to twelve apartments or implementing this model in an already existing housing facility would work best. This would allow for the development of a community without the feeling of being segregated and institutionalized. Individuals need to have access from

the apartments to the larger community and be able to easily access generic services such as banks, shops, churches, etc. In addition, it is recognized that transportation is frequently an isolating issue for many individuals. Therefore, in order for this model to work successfully, accessible van transportation must be included in the projected costs of operating such a model.

As stated previously in this document, many individuals reported that they spend a significant amount of time and stress in order to manage and maintain care through the PCA program. There is a growing trend among individuals with disabilities to accepting a lower standard of care because of PCA shortages and vulnerabilities, thus posing threats to an individual's health, safety, and well-being. In addition, many individuals stated that while the PCA program provided them the opportunity to live independently, they spent so much time maintaining the program that they had little time or energy left for living. Therefore, the aspect of running a PCA program has been given a great deal of emphasis in UCP's proposed model of services.

In the proposed model, individuals would continue to maintain maximum control over the supports in their lives. However, in this proposed model, case management staff would be available to assist with management responsibilities when an individual feels he or she would like some relief. In addition, an able-bodied individual would be available on site 24 hours a day to provide for emergency or intermittent needs that arise outside of regularly scheduled PCA hours. The case management staff would assist individuals in this program with coordinating the resources of PCAs. When several individuals live in close proximity to each other, they can hire the same attendants and the PCAs can more easily accommodate the short shift increments that are frequently associated with the person's needs. This would allow for the best use of an individual's allotted PCA hours and give him or her access to a higher quality of care. In addition, when several individuals work with a group of PCAs, it naturally establishes a built in back-up system. It is expected from the information obtained from the site visits that a more coordinated and supported PCA system benefits the attendants as well. PCAs reported feeling less isolated and more connected to a team of care for the individual they were assisting. By reducing the stress caused by dependence on the PCAs, a healthier lifestyle will ensue for all parties.

This proposed model takes into consideration that not all individuals have the ability or desire to manage or be involved in all aspects of the running of the PCA program at any given stage in their lives. Therefore, case management staff would tailor supports to each person's desires and needs. As needed, a case manager could operate the program on behalf of an individual while keeping him or her involved to whatever degree he or she were comfortable.

One of the aforementioned concerns for many individuals with disabilities is the isolation felt from being one of very few young to middle-aged individuals with disabilities living in a building predominantly occupied by elders. By making several accessible apartments available in a single location, individuals would not be subjected to the stress associated with always being different. As supported in the survey and site visits,

individuals with disabilities desire increased access to social opportunities as well as relationships with members of their peer groups. In UCP's proposed model, space would be available where individuals could gather. A variety of social and recreational activities would be sponsored. As requested in the survey results, these activities would include educational opportunities, games, music, guest speakers, outings, arts and crafts, movies/shows, and support groups.

## **FUNDING RESEARCH OUTCOMES**

Through UCP of MetroBoston's extensive experience in property management, as well as a comprehensive look into the current housing market, it is in our opinion that the implementation of this proposed model will require three funding necessities. One funding resource would be necessary for the physical design, one resource for the rental subsidy to ensure affordability and another funding resource for the staffing/supported operations and transportation living component identified in the survey research.

In researching the various available housing resources, a careful analysis of the affordable housing options in the state of Massachusetts was conducted. Although described as a very disjointed and complex system by both individuals with disabilities, their families, and field professionals, there are basically three avenues in which to obtain affordable housing; private, public, and Section 8 vouchers. Contributing to the complexity of this system is that all of these programs operate independently of each other while providing the same service which allows for eligible tenants to afford for market rental units through subsidizing all but 30% of the tenants' annual income. While public and private housing facilities require the completion of applications for each housing location, the acquisition of Section 8 vouchers additionally requires watching for housing authorities to open their Section 8 wait lists and then responding within the allotted time. To increase the applicants' odds of getting housing, the applicants are required to keep the housing authority updated as to their address and housing need as changes arise as housing authorities establish wait lists by both lottery and level of need.

To implement the physical design of this model, the following viable options were considered: building a small apartment complex, renovating an existing apartment complex, or acquiring rental units within an already existing private/public housing entity. In researching each of these options, the following describes potential opportunities and challenges associated with each option.

Similar to UCP of Rhode Island's Kara Estates, building through the use of HUD grants and other related property development programs represents the best way to ensure affordable housing sensitive to the needs of individuals with disabilities. Through contacts with housing authorities and housing advocates, this option provides the greatest opportunity for flexibility in design as well as being easier to acquire given the saturation of the current housing market. This option, while more feasible than acquiring units in an existing public/private housing facility, would require funding resources for assistance

with the completion of the HUD applications. It was recommended that agencies not experienced with the HUD requirements secure consultation services throughout the entire development process.

Through our research efforts, an alternative to building and/or acquiring traditional rental units was identified. In the state of Massachusetts, there are many assisted living programs not operating to full capacity. Because of the high vacancy rate associated with these programs, this alternative was researched as many of these facilities are considering the option of sub-letting units in an effort to maximize capacity. These facilities offer fully accessible, self-contained apartments where the opportunity for socialization exists without compromising one's independence. One identified obstacle in considering this as a housing option in which to implement our proposed model is the rental costs of these units. Because these units are not eligible for a traditional HUD rental subsidy or Section 8 voucher, this alternative option would require a non-traditional funding resource to provide a rental subsidy.

In addition to the implementation of the physical design of this model, the staffing/supported living component essential to this model was also researched for feasibility. With the exception of those individuals with disabilities who are fully funded through one of the state agencies, there are currently no resources available for the proposed staffing/supported living component. Precedent exists for the various state agencies to provide funding for more intensive supports for those individuals who require them in order to live a more satisfying life by feeling safer and less overwhelmed by some of the stressors identified with independent living.

Using the funding resources of ten individuals with disabilities who are not fully funded by a state agency, the average cost of their supported living services is \$50,337 per year. This annualized figure represents an average cost of these individuals case management services (5.4 hours per week) and personal care assistance (72 hours per week). These statistics support the survey results in that the average person not fully funded only has access to supports 46% of their week. For the remaining 54% of their week, these individuals are potentially isolated with very limited access to supports for spontaneous needs specific to personal care assistance, safety, and socialization. These statistics further support the survey results and the reason why many individuals with disabilities are in fact looking for an alternative model of supported living.

These statistics also validate the physical design of this proposed model. In addition to addressing the social and emotional interests of individuals with disabilities, the implementation of the staffing component proposed in this model requires that individuals live in close proximity to one another so that this support is easily accessible. Using a rate comparable to a personal care attendant, the programmatic cost of having shared access to a staff person 24-hours per day would be approximately \$1,700 per week. The additional costs of this model would include an individual to assist with social and recreational needs and an accessible vehicle.

To make this possible when tax benefits and administrative costs are included, the total increase in funding needed reaches approximately \$151,882.00. However when shared by ten to fifteen tenants living in this type of model, it translates to an average additional cost per person of only \$10,000.00 - \$15,000.00. Although this is an increase to the cost of an individual's supported living services, it provides for support missing and remains significantly lower than the cost associated with institutionalizing, an option considered by several individuals surveyed.

## **ACTION PLAN**

Through our outreach with field professionals and potential funding sources, UCP has encountered a great deal of support in the design of this proposed model. We have learned that there are numerous individuals who are asking for a more supportive alternative than what the independent living philosophy dictates. The success of this model relies on the acquisition of a financial commitment from those agencies that currently do not fully fund the individuals they support. The first step towards implementing this alternative model of supported living will require advocating with funders, disability activists, state legislators, and funding sources.

Because history shows that advocating for increased funds is a long endeavor, UCP of MetroBoston is currently working with the Department of Mental Retardation toward piloting this proposed model through the statewide nursing home initiative. Through this initiative, there is great need and opportunity to implement an alternative housing option for many fully funded individuals supported through the Department of Mental Retardation. Many of these individuals and their families are looking for an alternative to their current placement in a nursing home, however, they have clearly identified their trepidation with independent living opportunities. UCP, using the research from this project, has proceeded in the negotiation of five units in an assisted living facility where the level of supports needed by these individuals corresponds with the design of this proposed model. Because of DMR's financial commitment to meeting the needs of these individuals, the opportunity to implement this model has been well received.

By advocating for the support of this model, we are not advocating in opposition of independent living. Through our research findings, we are simply advocating for an alternative model of supported living for those individuals interested where some of the stressors identified with independent living are removed in an effort to ensure the opportunity for a fulfilling life. The challenges will remain in gaining the necessary philosophical and financial support of this model from those state agencies that do not fully fund programs.

Attachment A:

# HOUSING SURVEY

## Consumer Information:

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone Number: \_\_\_\_\_

E-mail Address: \_\_\_\_\_

How long have you lived in your current residence? \_\_\_\_\_

Age Range: 18-25      25-30      30-40      40-50      50 and older

Primary Disability: \_\_\_\_\_

Ethnicity (response optional):

Asian

Black/African American

Caucasian

Cape Verdean

Hispanic

Native American

Pacific Islander

Other: \_\_\_\_\_

How did you find your current housing? \_\_\_\_\_

\_\_\_\_\_

Do you live in subsidized housing?      YES              NO

Do you have a Section 8 voucher?      YES              NO

What barriers or difficulties do you/did you face when looking for a place to live?

- a) availability
- b) accessibility to public transportation
- c) cost
- d) accessible facilities
- e) desirable locations
- f.) other \_\_\_\_\_

If you were on a waiting list, how long did you wait? \_\_\_\_\_

Did you receive assistance in your housing search?      YES              NO

From who? \_\_\_\_\_

How many bedrooms does your home have? \_\_\_\_\_

How many bathrooms does your home have? \_\_\_\_\_

Do you feel your home has adequate space?      YES              NO

Why or why not? \_\_\_\_\_

Do you consider your home physically accessible?      YES              NO

To what degree was your home accessible when you moved in?

\_\_\_\_\_ Completely (access to all aspects of your home)

\_\_\_\_\_ Moderately (access to most aspects of your home)

\_\_\_\_\_ Inaccessible (limited access to most of your home)

Who was responsible for making your home accessible? \_\_\_\_\_

Are there more improvements needed to make your home more accessible?

YES NO

Please list:

Do you feel safe in your home? YES NO

Do you feel safe in your neighborhood? YES NO

Do you live alone? YES NO

If not, who do you live with? \_\_\_\_\_

Do you receive personal care assistance? YES NO

Homemaking Services? YES NO

How many hours per week? \_\_\_\_\_

Do you have a nighttime attendant? YES NO

Do other people with disabilities live in your housing facility?

YES NO

Which of the following would best describe your current living situation?

- a.) single apartment
- b.) group home
- c.) shared apartment
- d.) own house
- e.) shared house
- f.) nursing home

How would you best describe the other tenants in your building?

- a.) Elderly
- b.) Families
- c.) Young to middle aged adults
- d.) Adults with disabilities
- e.) Mixed

Does your housing facility offer recreational activities? YES NO

Is there a common space for recreational activities in your housing facility?  
YES NO

Is this accessible to you? YES NO

Do you participate in these activities? YES NO

Why or why not? \_\_\_\_\_  
\_\_\_\_\_

Which of the following would you participate in if available to you?

games	exercise	music	shared meals
arts and crafts	education	support groups	outings
movies/shows	guest speakers	other : _____	

Are you satisfied with your current living situation? YES NO

Why or why not? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

What problems/difficulties have you faced in your current living situation?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Are there things you would like changed in your current living situation?

YES NO

Please list:  
\_\_\_\_\_  
\_\_\_\_\_

Are there supports missing in your life? YES NO

Describe your ideal living situation: \_\_\_\_\_

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As you answer the questions below, please indicate level of importance using the following scale:

**1 no impact or not at all important**  
**5 significant impact/extremely important**

Are you living in a town where you want to live? YES NO

*If yes:* How much did this impact your decision of where to live?

1 2 3 4 5

***If no:* Would you consider another living situation so you could live in the town of your choice?**

**YES NO MAYBE**

And how much would this impact the quality of your life?

1 2 3 4 5

**Is your home accessible by public transportation? YES NO**

*If yes:* How much did this impact your decision of where to live?

1 2 3 4 5

*If no:* Would you consider another living situation where this support was available?

**YES NO MAYBE**

And how much would this impact the quality of your life?

1 2 3 4 5

Does your current place of residence offer transportation? YES NO

*If yes:* How much did this impact your decision of where to live?

1 2 3 4 5

*If no:* Would you consider another living situation where this support was available?

**YES NO MAYBE**

And how much would this impact the quality of your life?

1 2 3 4 5

Do you have on-call maintenance available to you for all household repairs?

YES NO

*If yes:* How much did this impact your decision of where to live?

1 2 3 4 5

*If no:* Would you consider another living situation where this support was available?

YES NO MAYBE

And how much would this impact the quality of your life?

1 2 3 4 5

Do you have an able-bodied person available to you at all times now?

YES NO

*If yes:* How much did this impact your decision of where to live?

1 2 3 4 5

*If no:* Would you consider another living situation where this support was available?

YES NO MAYBE

And how much would this impact the quality of your life?

1 2 3 4 5

Do you currently share staff/PCAs with other tenants?

YES NO

*If yes:* How much did this impact your decision of where to live?

1 2 3 4 5

*If no:* Would you consider another living situation where several individuals shared PCAs?

YES NO MAYBE

How much would this impact the quality of your life?

1 2 3 4 5

Do you share a NightTime Attendant with other tenants? YES NO

*If yes:* How much did this impact your decision of where to live?

1 2 3 4 5

*If no:* Would you consider another living situation where several individuals shared an NTA? YES NO MAYBE

How much would this impact the quality of your life?

1 2 3 4 5

Is your current living space designed specifically for people with physical limitations? YES NO

*If yes:* How much did this impact your decision of where to live?

1 2 3 4 5

*If no:* Would you consider another living situation where this support was available? YES NO MAYBE

How much would this impact the quality of your life?

1 2 3 4 5

**Do you currently have a pet? YES NO**

*If yes:* How much did this impact your decision of where to live?

1 2 3 4 5

*If no:* Would you consider another living situation where this support was available? YES NO MAYBE

How much would this impact the quality of your life?

1 2 3 4 5

**Additional Comments/Suggestions:** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

*Interview Date:* \_\_\_\_\_

*Interviewer Name:* \_\_\_\_\_

Attachment B:

# HOUSING SURVEY

## Family/Caregiver Survey

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone Number: \_\_\_\_\_ E-mail Address: \_\_\_\_\_

Relationship to individual: \_\_\_\_\_

How long have you know the individual? \_\_\_\_\_

Individual's Primary Disability: \_\_\_\_\_

Age Range of Individual:

18-25      25-30      30-40      40-50      50 and older

Your Age Range:

18-25      25-30      30-40      40-50      50 and older

Individual Ethnicity (response optional):

Asian

Black/African American

Caucasian

Cape Verdean

Hispanic

Native American

Pacific Islander

Other: \_\_\_\_\_

How long has this individual lived in their current residence? \_\_\_\_\_

Where did they live before? \_\_\_\_\_

How did they find their current housing? \_\_\_\_\_

\_\_\_\_\_

Do they live in subsidized housing?    YES            NO            Unsure

Do they have a Section 8 voucher?    YES            NO            Unsure

What barriers or difficulties do you remember the individual facing when looking for a place to live?

f) availability

g) accessibility to public transportation

h) cost

i) accessible facilities

j) desirable locations

g.) other \_\_\_\_\_

If the individual was on a waiting list, how long did they wait? \_\_\_\_\_

Did the individual receive assistance in their housing search?

YES

NO

Unsure

From whom? \_\_\_\_\_

How many bedrooms does the individuals home have? \_\_\_\_\_

How many bathrooms does their home have? \_\_\_\_\_

Do you feel their home has adequate space?

YES

NO

Why or why not? \_\_\_\_\_

Do you consider their home physically accessible?

YES

NO

To what degree was their home accessible when they moved in?

\_\_\_\_\_ Completely (access to all aspects of your home)

\_\_\_\_\_ Moderately (access to most aspects of your home)

\_\_\_\_\_ I inaccessible (limited access to most of your home)

Who was responsible for making their home accessible?

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Are there more improvements needed to make the individuals home more accessible? YES NO

Please list:

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Do you feel the individual's home is safe? YES NO

Do you feel that the individual feels safe in their home? YES NO

Do you feel the individual lives in a safe neighborhood? YES NO

Does the individual live alone? YES NO

If not, who do you live with? \_\_\_\_\_

Does the individual receive personal care assistance? YES NO

Homemaking Services? YES NO

How many hours per week? \_\_\_\_\_

Does the individual have a nighttime attendant? YES NO

Do other people with disabilities live in their housing facility?  
YES NO

Which of the following would best describe their current living situation?

- g.) single apartment
- h.) group home
- i.) shared apartment
- j.) own house
- k.) shared house
- l.) nursing home

How would you best describe the other tenants in their building?

- b.) Elderly
- b.) Families
- d.) Young to middle aged adults
- d.) Adults with disabilities
- f.) Mixed

Does their housing facility offer recreational activities? YES NO

Is there a common space for recreational activities in their housing facility?  
YES NO

Is this accessible to them? YES NO

Do they participate in these activities? YES NO

Why or why not? \_\_\_\_\_

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Which of the following do you think the individual would participate in if available to them?

games	exercise	music	shared meals
arts and crafts	education	support groups	outings
movies/shows	guest speakers	other : _____	

Are you satisfied with the individual's current living situation? YES NO

Why or why not? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

What problems/difficulties has the individual faced in their current living situation?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Are there things you would like changed in their current living situation?

YES NO

Please list:

\_\_\_\_\_  
\_\_\_\_\_

Are there supports missing in their life?

YES NO

Describe your ideal living situation for the individual: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

As you answer the questions below, please indicate level of impact/importance using the following scale:

**1 no impact or not at all important**  
**5 significant impact/ extremely important**

Is the individual living in a town where they want to live? YES NO

If yes: How important is this to you/individual?

1 2 3 4 5

If no: How much would this impact their quality of life?

1 2 3 4 5

Is their home accessible by public transportation? YES NO

If yes: How important is this to you/individual?

1 2 3 4 5

If no: How much would this impact their quality of life?

1 2 3 4 5

Does their current place of residence offer transportation? YES NO

If yes: How important is this to you/individual?

1 2 3 4 5

If no: How much would this impact their quality of life?

1 2 3 4 5

Do they have on-call maintenance available for all household repairs?

YES NO

If yes: How important is this to you/individual?  
1 2 3 4 5

If no: How much would this impact their quality of life?  
1 2 3 4 5

Do they have an able-bodied person available to you at all times now?  
YES NO

If yes: How important is this to you/individual?  
1 2 3 4 5

If no: How much would this impact their quality of life?  
1 2 3 4 5

Do they currently share staff/PCAs with other tenants? YES NO

If yes: How important is this to you/individual?  
1 2 3 4 5

If no: How much would this impact their quality of life?  
1 2 3 4 5

Do they share a NightTime Attendant with other tenants? YES NO

If yes: How important is this to you/individual?  
1 2 3 4 5

If no: How much would this impact their quality of life?  
1 2 3 4 5

Is their current living space designed specifically for people with physical limitations? YES NO

If yes: How important is this to you/individual?

1 2 3 4 5

If no: How much would this impact their quality of life?

1 2 3 4 5

Does the individual currently have a pet? YES NO

If yes: How important is this to you/individual?

1 2 3 4 5

If no: How much would this impact their quality of life?

1 2 3 4 5

For some or all of the supports or services surveyed above, would the individual consider relocating to obtain these services. YES NO  
Which services/supports are most influential to a decision to relocate.

**Please list:**

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Date of Interview: \_\_\_\_\_

**Interviewer's Name:** \_\_\_\_\_