

THE GRAYING OF PEOPLE WITH INTELLECTUAL AND  
DEVELOPMENTAL DISABILITIES:  
ORGANIZATIONAL EFFORTS OF COMMUNITY SERVICE PROVIDERS  
IN ADAPTING FACILITIES AND PROGRAMMING  
TO MEET THE NEEDS OF OLDER ADULTS

by

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A dissertation submitted to the Graduate Faculty in Social Welfare in partial fulfillment of the requirements for the degree of Doctor of Philosophy, The City University of New York

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This manuscript has been read and accepted for the  
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## Abstract

THE GRAYING OF PEOPLE WITH INTELLECTUAL DISABILITIES:  
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Advisor: Professor Michael J. Smith

People with intellectual and developmental disabilities are living longer, thereby creating unique challenges for the aging and disabilities networks. This qualitative multi-case study explored the ways in which six community service organizations serving people with intellectual and developmental disabilities have adapted their facilities and programming in response to the growing cohort of older persons in their care. The study focused on the following adaptations: physical plant, financial models, workforce, medical care and programming. Twenty-two in-depth interviews were conducted with executive-level staff of the six participating organizations. Data was triangulated through examination of archival data, organizational documents, agency web sites, and publicly available financial records. A cross-case comparison assessed the extent to which organizational characteristics promoted or impeded an agency's ability to make the adaptations necessary to facilitate the aging in place of its older consumers. The following theories contributed to the underlying framework of the study: successful aging, resource dependence, and structural inertia. Study findings indicated that the physical, financial and bureaucratic barriers play a more significant role in impeding or facilitating an agency's ability

to make the adaptations necessary than does an agency's affiliation, complexity or relative size.

Discussed are the policy implications related to the growing number of older persons with intellectual and developmental disabilities as well as recommendations for future study.

Dedication

To my beloved mother

**Eugenia DiBernardi Corrado**

**1937 – 1992**

for imparting your  
thirst for knowledge,  
love of books,  
compassion for the underdog,  
enduring values,  
integrity, perseverance, dignity and  
*your love* -  
an inheritance beyond measure

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## Chapter I. Introduction

It is predicted that by the year 2030, the number of persons in the United States ages sixty-five and older will more than double to 72.1 million, or over 20 percent of the population, with the number of persons ages eighty-five and older increasing to 8.7 million, or over 2.3 percent of the population (Census Bureau, 2008). This increase in the population of seniors has a significant impact on community providers who serve older adults. Persons with intellectual and developmental disabilities are also living longer due to better health care, nutrition, and social conditions, as well as to the positive outcomes of deinstitutionalization (Doka & Lavin, 2003; Janicki, 1999). In concert with the general older adult population, these individuals' special needs for care will impose added pressures on long-term care resources and both informal and formal supports, challenging both the aging and the developmental disabilities networks to meet their growing needs for relevant and integrated services (Doka & Lavin, 2003; Janicki, Knox & Jacobson, 1985; Parish & Lutwick, 2005; Roberto & Nelson, 1989).

### Changing Demographics of the Intellectually Disabled Population

According to the American Association of Intellectual and Developmental Disabilities (AAIDD), an estimated six hundred thousand to one million individuals in the United States over age sixty with intellectual and developmental disabilities can now expect a life span that approximates that of the general population. In 1930, individuals with Down syndrome had a typical life expectancy of fifteen years for males and twenty-two years for females, but now have an average life expectancy of 55.8 years (Janicki, Dalton, Henderson & Davidson, 1999). This increase in life expectancy for individuals with Down syndrome occurs at a significantly

accelerated rate compared with either the general non-disabled population or the general intellectually disabled population, even as those affected continue to experience health declines and disease processes such as dementia (Coppus, et al., 2006; Janicki, et al., 1999, Janicki, Heller, Seltzer & Hogg, 1996). Other health-related factors include a high prevalence of obesity in women with Down syndrome (Melville, Cooper, McGrother, Thorp, Callacott, 2005), as well as dietary insufficiency and low rates of exercise (Emerson, 2005) as compared to the general population of persons with intellectual and developmental disabilities. “The health status needs of adults with an intellectual disability change with advancing age, and are often accompanied by difficulties with vision, hearing, mobility, stamina and some mental processes” (Janicki, Davidson, Henderson, McCallion, Taets, Force, et al., 2002, p. 287). It is estimated that in the United States, nine thousand persons with intellectual and developmental disabilities, including those with Down syndrome, have dementia, and that number is expected to double by 2020 (Janicki & Dalton, 2000). In addition, the overall life expectancy for those in the general population of persons with intellectual and developmental disabilities has grown to seventy-one years of age (Heller, Caldwell & Factor, 2007), with “cause of death similar to the general population with cardiovascular, respiratory and neoplastic diseases among the most prominent causes of death” (Janicki, et al., 1999, p. 284).

Janicki & Wisniewski (1985) were pioneer social researchers who anticipated this growing demographic and called for the gerontological and disabilities communities to begin to identify and develop approaches to deal with the growing population of older adults with intellectual and developmental disabilities. At that time, few social researchers focused on this topic or published articles about it. Janicki and Wisniewski (1985, p. 3) stated, “Social research of any significance in the area of aging and developmental disabilities is virtually nonexistent.” Although

researchers have begun to identify the salient issues and approaches to working with older adults with intellectual and developmental disabilities during the past two decades, there is a gap in the research literature examining the lived experience of community service providers in meeting the needs of this growing population. For example, recent research findings indicate that there is a genetic link for early onset dementia in females with Down syndrome (Shupf, et al., 2008). In light of these findings, agency administrators may benefit from taking client case mix into consideration when reviewing potential admissions into their residential programs, resulting in a propensity to “cream” the cases they accept, consequently under serving and compromising the individual’s right to care. In this example, since there is an increased probability that an adult female consumer with Down syndrome will develop early onset dementia and require an intensive level of very costly support services, an administrator may opt to decline admission in favor of a higher functioning non–Down syndrome intellectually disabled consumer. The consequence of providing quality services to a high need and medically frail population of older adults with intellectual and developmental disabilities may have financial implications that put an entire organization at risk. At the very least, knowing the high probability that a potential consumer has of developing dementia may pose an ethical dilemma for administrators who need to factor in case mix when making decisions about whom to admit, or not admit, into a residence. This is just one example of the important programmatic and financial impacts on organizations that will result from the aging of their consumers and, consequently, on the types of decisions that agency administrators will need to make relative to serving this population.

Planning for these demographic shifts, especially as they relate to medically frail consumers, is a recent phenomenon. For some agencies, this is uncharted territory, presenting challenges to the service network that cares for people with intellectual and developmental disabilities as they

age in place. Understanding the complexities and challenges involved in transforming organizations that serve older adults with intellectual and developmental disabilities as they age and develop increased needs for care will not only lead to better program designs to serve this population, but will also assist in maintaining an organization's legitimacy and financial viability.

This qualitative study helps fill the gap in research by illuminating ways in which a heterogeneous sample of six community-based not-for-profit service providers throughout New York State, serving persons with intellectual and developmental disabilities, have adapted their services and facilities to accommodate a growing cohort of medically frail older adults. Within the conceptual and analytical frameworks of gerontological and organizational theory, the study explores the ways in which these community-based service providers have already responded, or plan to respond, to the growing number of older persons with intellectual and developmental disabilities in their care. Chief executive officers, chief fiscal officers, chief operating officers, clinical directors, and program directors — twenty-two in all, were interviewed and these interviews formed the basis of the qualitative inquiry.

The focus of the study was to examine how each of these organizations promoted successful aging in place of its consumers by making necessary adaptations to serve an older population of persons with intellectual and developmental disabilities. . The study concentrated on the following themes that emerged from a review of the pertinent literature and from my experience in the fields of aging and disabilities:

- funding and resource allocation issues;
- medical and health issues;
- physical plant issues;

- specialized programming; and
- workforce issues.

The study findings include a discussion of the role that organizational characteristics such as size, complexity, and affiliation play in impeding or promoting the organization's ability to make the necessary accommodations that assist older consumers to successfully age in place. More specifically, the study attempts to define what is needed to provide better care for older persons with intellectual and developmental disabilities, with special emphasis on the medically frail, as well as to identify the contextual issues and resources necessary to facilitate the provision of appropriate and effective care for older consumers. More specifically, the study explored how participant service organizations have addressed:

- capacity issues;
- demands of medically frail aging consumers;
- how fiscal challenges were mitigated;
- physical plant adaptations or the need to build new facilities to better accommodate older consumers and the changes in programming attributed to this growing population; and
- training and development needs of staff.

The three primary research questions explored in this study were:

1. How have community service agencies adapted their facilities, funding models, services, supports, staffing, and programming to accommodate the aging of their consumers with intellectual and developmental disabilities?
2. To what extent have these accommodations promoted the successful aging in place of their older consumers with intellectual and developmental disabilities?

3. What type of agency (single-purpose or multipurpose; faith-based or secular; medium-size or large-size) is best suited to make adaptive responses to the growing number of older adults with intellectual and developmental disabilities?

Information gleaned from the study illuminates best practices in terms of administration and program design. The study also informs decision-making, thereby contributing to the research and practice knowledge base in the aging and disabilities arenas. More specifically, the study elaborates on what is needed to provide better care for older persons with intellectual and developmental disabilities, with special attention to the medically frail. There are benefits to studying how other organizations have implemented programs that address challenging issues since, as Schorr (1989, p. 266) states:

Model programs—no matter how special their circumstance—bring home that, even in an imperfect world, something can be done to address seemingly intractable social problems. They provide a vision of what can be achieved, a benchmark for judging others' efforts, and—at a minimum—a takeoff point in search of better understanding of the elements of interventions worthy of widespread implementation.

As a result of the study, we not only have a better understanding of the challenges facing community-based voluntary service providers who serve older adults with intellectual and developmental disabilities; the resulting efforts also, according to Schorr (1989), “spotlight the attributes of effective services and supports” (p. 266) and elucidate less effective organizational practices.

#### Organizational Challenges: A Case Illustration of the Problem

My interest in the study topic emanated from the challenges I have encountered over the past two decades as an administrator of programs serving the general population of older adults and my responsibility, in recent years, for the portfolio of services for persons with intellectual and

developmental disabilities which my agency sponsors. My employer, Catholic Charities Neighborhood Services (CCNS), Inc., a large multiservice organization serving the boroughs of Brooklyn and Queens in New York City, has faced seemingly insurmountable challenges over the past several years in meeting the needs of its aging consumers with intellectual and developmental disabilities. CCNS has been serving persons with intellectual and developmental disabilities in a variety of settings since 1973. Presently, within Catholic Charities' Services for Persons with Developmental Disabilities (SPDD) division, CCNS serves 204 residents in twenty group homes, another 195 individuals in day habilitation programs, and 300 families in the community by providing Medicaid Service Coordination, community habilitation, family support, and respite services. A review of 198 consumer case files in February 2012 showed that there has been a marked increase (26 percent) during the past decade in the number of consumers living in CCNS-sponsored residences who are over the age of fifty. As illustrated in Table 1.1, 73 percent of these consumers have resided in CCNS residential programs for thirty or more years, and several of them are now septuagenarians and octogenarians. As these consumers have aged, their needs have also changed relative to the level of services required to care for them safely within CCNS' residential settings. Many have developed new or exacerbated behavioral issues, mobility impairments, vision loss, insulin dependence, dementia, and osteoporosis and/or other specialized medical needs, which represent tremendous challenges to meet within CCNS residential programs

Table 1

*Percentage of Residents 50 Years of Age and Older*

Resident Age	2012	2002	% change
50 and older	92 (46%)	40 (20%)	+ 26%
Under 50	106 (54%)	158 (80%)	- 26%
Total	198 (100%)	198 (100%)	

The following descriptive samples of several consumers living at a CCNS sponsored Intermediate Care Facility (ICF-DD), which is home to seventeen individuals between the ages of fifty and eighty-one, help to delineate the varied level and range of services that CCNS is challenged to provide to meet these consumers' needs:

A.A. is a seventy-five-year-old non-ambulatory male diagnosed with profound mental retardation, severe contractions of the lower extremities, osteoporosis, seizure disorder, and depression. In July 2008, he underwent a urethral prostrate resection. A.A. is only able to express his wants and needs through one-or two-word utterances. A.A. relies on staff to assist him physically with all activities of daily living (ADL) tasks, although A.A. can use an electric shaver and rinse his dentures with hand over hand guidance. A.A. is assigned one-to-one staff coverage twenty-four hours a day, seven days a week, due to his medical frailty and need for physical assistance, especially in the event of an emergency situation or during fire drill evacuations. A.A. requires:

- physical therapy to address limited range of motion in his upper and lower extremities, muscle weakness, and decreased sitting and balance coordination ;

- occupational therapy to help strengthen his upper extremities and increase coordination related to self-care;
- specialized dietary services and is fed through a stomach peg;
- staff assistance, with medication administration and management as he is not self-medicating; and
- staff supervision to go out into the community.

A.A. displays the effects of aging in slower movements and frequent fatigue. A.A. also receives behavior medication, and the staff utilizes a behavior modification plan to address recurring depressive behaviors including refusal to participate in activities, unresponsiveness, and crying, and drooping head. Between July 2008 and June 2009, A.A. was hospitalized six times for a transurethral resection of the prostate, a fractured femur, hematoma, bronchitis, pneumonia, COPD (Chronic Obstructive Pulmonary Disease) exacerbation, and deep venous thrombosis. History of intensive rehabilitative stays in a skilled nursing home setting followed two of the hospitalizations. A.A. required one-to-one support, twenty-four hours a day, from CCNS staff throughout his hospitalizations and rehab stays.

B.A. is a sixty-seven-year-old female with a primary diagnosis of moderate mental retardation and secondary diagnoses of schizoaffective disorder, hypothyroidism, lower hemi-paresis, lipidemia, osteoporosis, dementia, and Parkinson's disease. B.A. ambulates with the use of a wheelchair. B.A. also has numerous behavioral problems of which the frequency and intensity have increased during the past year. B.A.'s behavior modification plan and medication focus on addressing behaviors including yelling, rocking, flashing hands, hitting, kicking, pushing, head-butting, biting, pulling staff's hair, scratching, and throwing food and personal items. Due to

B.A.'s behavioral instability and the difficulty she has experienced in following the daily routine at her day program, she now receives individualized day habilitation services in the residence.

B.A. fully depends on staff for assistance in:

- completing ADL, all aspects of personal hygiene and most independent living tasks;
- evacuating the residence in the event of a fire drill or other emergency; and
- meeting all health and medication needs.

Due to gastrointestinal problems, B.A. receives a high fiber, soft diet. B.A. was hospitalized three times during the period from July 2008 through December 2008 for abdominal distension, voluminous sigmoid and colostomy surgery during which the CCNS residence program provided her with one-to-one support twenty-four hours a day. A six-month stay in a skilled nursing facility followed B.A.'s last hospitalization for colostomy rehabilitation, where she also required one-to-one support from CCNS staff twenty-four hours a day.

C.A. is an eighty-one-year-old male with a primary diagnosis of severe mental retardation. C.A. currently ambulates with the use of a wheelchair and transfer belt. C.A. exhibits behavioral problems, which include cursing and yelling, physically threatening behavior, spitting, repetitive speech, and skin picking. This manifestation of symptoms is treated with a behavioral modification plan and medication. C.A. also has shown signs of aging as his attention span and stamina have decreased. C.A. requires:

- physical therapy to help maintain his current range of motion, transfer ability, gait quality, strength, flexibility, wheelchair positioning, and balance;
- occupational therapy to improve deficits in ADL self-care management and to improve eating skills;

- specialized nutrition services for menu planning to maintain an 1,800-calorie, high fiber, low fat, low cholesterol, mechanically chopped, honey-consistency diet;
- staff assistance to complete most of his ADL and medication management and administration; and
- staff assistance and advocacy with medical appointments to ensure that appointments are kept and care recommendations are followed as ordered.

C.A. receives close supervision from staff during all waking hours in the residence and one-to-one support at his day program. Between September 2008 and June 2009, C.A. was hospitalized three times for acute cardiac syndrome, pneumonia, and left leg edema, during which time he required one-to-one support from CCNS staff twenty-four hours a day.

The above case examples depict the level of frailty and complex medical needs that are consistent with a geriatric population of persons with intellectual and developmental disabilities. These case examples also justify the robust staffing levels required to assist non-ambulatory and nonverbal consumers and to ensure that they are closely supervised, monitored, and cared for in a safe environment. The high level of medical complexity warrants primary medical care, nursing services, and services of other allied health professionals such as nutritionists, pharmacists, physical therapists, occupational therapists, and speech pathologists. As consumers age, their behavioral symptomatology may exacerbate, requiring more intense clinical interventions from behavioral health professionals such as psychiatrists or psychologists who specialize in behavioral interventions. Generally, older adults take several medications to manage their chronic and acute conditions, which require medication management to review, monitor, and properly administer their medications. For example, by regulation, consumers with

brittle diabetes can receive their insulin shots only from a registered nurse as opposed to a less costly nurse's aide or direct care staff. Medically frail and behaviorally challenged older adults are frequently assigned one-to-one coverage, often twenty-four hours a day, seven days a week—all costly but necessary reinforcements employed to keep the individuals safe and, to the extent possible, involved in active treatment and maintained at their optimal level of functioning.

CCNS residences for persons with intellectual and developmental disabilities are predominantly former rectories or convents that the agency leases from the Brooklyn diocese. Several residences, were originally funded as Community Residences (CRs), and then subsequently converted to Supervised Intermediate Residential Alternatives (IRAs), while others have been established and maintained as Intermediate Care Facilities (ICF-DDs). Regrettably, funding models have not kept pace with the actual expenditures required to provide quality services to this increasingly frail population; reimbursement rates have not been rebased for CRs since 1989 and for ICF-DDs since 1999. Although periodic rate adjustments are made to cover salary adjustments and other inflationary expenses, the significant increase in expenditures associated with providing a higher level of care to the growing cohort of aging and medically frail consumers is not included in the reimbursement rate at this time. Consequently, CCNS has been forced to subsidize existing funding streams from its own budget to ensure its ability to provide the appropriate levels of nursing care, physical therapy, occupational therapy, dietary services, and staffing in its homes for persons with intellectual and developmental disabilities. These funding subsidies generated by CCNS help ensure that the long-term care needs of residents can be met within the group homes, allowing them to age in place rather than having to pursue permanent nursing home placement. CCNS has submitted appeals for subsidy

recoupment to the New York State Office of Persons with Developmental Disabilities (OPWDD), related to the provision of higher level of care and services to aging intellectually disabled residents and other related expenses. It typically has taken anywhere from twelve months to three years before CCNS receives a determination and subsequent payment regarding these appeals. The recent New York State budget crisis has further prolonged the complex bureaucratic process of review and approval, since OPWDD now has far fewer employees to review appeals submitted to them by hundreds of voluntary agencies in its network. The protracted period required for the appeals process has placed added financial pressures on CCNS. Funding deficits, related to serving persons with intellectual and developmental disabilities, have continued to accumulate and increase over the years, creating significant cash flow challenges and, more importantly, severely compromising CCNS' overall fiscal health.<sup>1</sup>

The significance of an agency's having to overspend its approved budget to meet the needs of its aging consumers is an important one. Agencies without adequate reserves or lines of credit may not be able to subsidize their budgets to the extent necessary to meet their cash demands. Consequently, these agencies may be forced to divest their portfolios of programs for the intellectually disabled or end up facing bankruptcy; establishing lines of credit has been exceedingly difficult due to the banking crisis and ensuing recession. Other agencies have merged with larger organizations to remain fiscally viable, and still others may end up reverting sponsorship of programs back to OPWDD for the state to operate, counter to the prevailing direction of downsizing state facilities.<sup>2</sup> Reversion of programs back to OPWDD is a much more costly alternative given the reality that it costs the state more to operate programs directly than it

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<sup>1</sup> See Appendix A for graphic depiction of cumulative cash flow deficits as presented to Finance Committee of CCNS board of directors on October 6, 2009.

<sup>2</sup> The per diem Medicaid reimbursement rate per consumer in New York State developmental center is \$4,556 compared to an average rate of \$450 paid to the voluntary sector. (Pfeiffer, M.B., 2010)

would to increase funding to community service agencies struggling to provide appropriate care for their aging and increasingly frail consumers. Such was the case recently with a Catholic Charities affiliate agency in upstate New York when, after much deliberation, its board of trustees made the decision to extricate the agency from operating group homes for persons with intellectual and developmental disabilities—the cause of several years of cumulative deficits that the board decided was unsustainable.

Organizations overspend their budgets for a variety of reasons, including their inability to manage fiscal information, mismanagement of funds, unanticipated operational expenses, expensive and frequent emergency repairs (e.g., elevator repairs), inflationary pressures, overtime expenses, and other non-reimbursable items. At CCNS, not all deficit spending across budget categories is necessarily attributed to increased needs related to its growing cohort of aging consumers with intellectual and developmental disabilities. However, a review of backup documentation submitted with actual funding appeals, as well as an analysis of approved expenditures by OPWDD, confirmed that a significant portion of program deficits were related to the provision of services and staffing to address the needs associated with increased age and medical frailty (Tables 2 through 5). Over the four fiscal years, 2006 through fiscal year 2009, CCNS sustained a cumulative loss of close to \$18 million, of which CCNS eventually recovered 91 percent from OPWDD (Tables 1.5 through 1.9). It took CCNS eighteen to thirty-nine months to recoup its deficit, which included appeal submissions to OPWDD up to the time that OPWDD reimbursed the funds back to the agency. As mentioned earlier, this imposed tremendous financial hardships and cash flow pressures on CCNS. Deficit spending continued. However, the agency remained committed to providing quality care to its aging consumers. At the very least, there was validation on the part of OPWDD that the old funding paradigms no longer

sustained an agency that provided residential and community services to older physically and medically frail persons with intellectual and developmental disabilities.

Table 2

*Rate Appeals Submitted by CCNS Fiscal Year 2006/2007*

Residence type	Net deficit <sup>a</sup>	% Total ID budget
IRA	\$445,222	1.44%
CR	\$1,670,436	5.40%
ICF-DD	\$1,136,777	3.68%
Total Appeal	\$3,252,435	10.52%
Total exp FY 2006 <sup>b</sup>	\$30,906,012	

*Note.* From <sup>a</sup>2006 Consolidated Fiscal Report (CFR) with revisions submitted by CCNS to OPWDD and audited financials. <sup>b</sup> Portion of total CCNS spending related to service for persons with developmental disabilities as reported in 2006 IRS Income Tax 990 Form.

Table 3

*Rate Appeals Submitted by CCNS Fiscal Year 2007/2008*

Residence type	Net deficit <sup>a</sup>	% Total ID budget
IRA	\$1,311,282	3.96%
CR	\$1,993,447	6.02%
ICF-DD	\$1,503,739	4.53%
Total Appeal	\$4,808,468	14.51%
Total exp FY 2007 <sup>b</sup>	\$33,135,098	

*Note.* From <sup>a</sup>2007 Consolidated Fiscal Report and revisions submitted by CCNS to OPWDD and audited financials. <sup>b</sup> Portion of total CCNS spending attributed to services for people with developmental disabilities as reported in 2007 IRS Income Tax 990 Form.

Table 4

*Rate Appeals Submitted by CCNS Fiscal Year 2008/2009*

Residence type	Net deficit <sup>a</sup>	% Total ID budget
IRA	\$786,850	2.24 %
CR	\$1,660,109	4.72%
ICF-DD	\$2,335,907	6.63%
Total Appeal	\$4,782,866	13.59%
Total exp FY 2008 <sup>b</sup>	\$35,190,203	

*Note.* From <sup>a</sup> 2008 Consolidated Fiscal Report (CFR) submitted by CCNS to OPWDD and revisions. <sup>b</sup> Portion of total CCNS total expenses related to service for persons with developmental disabilities as reported in 2008 IRS Income Tax 990 Form.

Table 5

*Rate Appeals Submitted by CCNS Fiscal Year 2009/2010*

Residence type	Net deficit <sup>a</sup>	% Total ID budget
IRA	\$ 2,121,921	5.45 %
CR	\$ 849,574	2.18%
ICF-DD	\$ 2,118,953	5.45 %
Total Appeal	\$ 5,090,448	13.08%
Total exp FY 2009 <sup>b</sup>	\$ 38,912,926	

*Note.* From <sup>a</sup> 2009 Consolidated Fiscal Report (CFR) and revisions submitted by CCNS to OPWDD. <sup>b</sup> Portion of total CCNS spending expenses attributed to services for people with developmental disabilities as reported in 2009 IRS Income Tax 990 Form.

Table 6

*IRA Recoupment by CCNS Fiscal Years 2006/2007 through 2009/2010*


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Fiscal year	Amount appeal	Recoupment	% Total appeal
2006/2007	\$445,222	\$432,422	97.12%
2007/2008	\$1,311,282	\$1,268,448	96.73%
2008/2009	\$786,850	\$796,063	101.17%
2009/2010	\$2,121,921	\$2,106,329	98.67%
Total	\$4,665,275	\$4,603,262	98.67%

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*Note.* Recoupment based on signed contract award from OPWDD. 2008/2009 recoupment was higher than amount requested because an OPWDD review noted omissions of reimbursable expenditures.

Table 7

*Community Residence Recoupment by CCNS Fiscal Years 2006/2007 through 2009/2010*


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Fiscal year	Amount appeal	Recoupment	% Total appeal
2006/2007	\$1,670,436	\$1,414,606	84.68%
2007/2008	\$1,993,447	\$1,869,838	93.79%
2008/2009	\$1,660,109	\$1,202,415	72.43%
2009/2010	\$849,574	\$661,188	77.83%
Total	\$6,173,566	\$5,148,047	83.39%

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Table 8

*ICF-DD Recoupment by CCNS Fiscal Years 2006/2007 through 2009/2010*

Fiscal year	Amount appeal	Recoupment	% Total appeal
2006/2007	\$1,136,777	\$1,106,329	97.32%
2007/2008	\$1,503,739	\$1,268,448	84.35%
2008/2009	\$2,335,907	\$2,165,048	92.69%
2009/2010	\$2,118,953	\$2,106,329	99.40%
Total	\$7,095,376	\$6,646,154	93.67%

Table 9

*Total Recoupment (IRA, CR and ICF-DD) by CCNS Fiscal Years 2006/2007 through 2009/2010*

Type Residence	Total Appeals	Recoupment	% Total appeals
IRA	\$4,665,275	\$4,603,262	98.67%
CR	\$6,173,566	\$5,148,047	83.39%
ICF-DD	\$7,095,376	\$6,646,154	93.67%
Total	\$17,934,217	\$16,397,463	91.43%

In addition to the funding challenges that CCNS experiences as a result of caring for a growing number of aging consumers with intellectual and developmental disabilities who have high-level nursing needs, the agency struggles to accommodate the growing

mobility impairments of consumers, given the lack of handicap accessibility in several of its residential facilities. Many of the agency's parish-based properties do not have elevators or wheelchair-accessible doorways or bathrooms. Often, as a short-term remedy, CCNS converts common spaces on the first floor of several residences to accommodate consumers who were mobility-impaired and who previously lived on higher floors. This relocation of consumers' rooms addresses accessibility issues as well as fire and other safety concerns, but it also negatively affects the availability of congregate living space for all of the residents. These room relocations represent short-term, practical solutions even though they impose inconveniences and hardship on housemates. However, they are not sufficient to accommodate all of the consumers with intellectual and developmental disabilities who are aging in place within the residences.

As the number of persons with intellectual and developmental disabilities live longer, CCNS staff have required increased training in providing care for frailer consumers and those with dementia, as well as enhanced education on aging issues to help ensure their sensitivity to the needs of older adults and knowledge of end-of-life issues. In the past year, two CCNS long-term residents could have benefited from receiving hospice care. However, these instances posed ethical and moral dilemmas for agency administration, nursing, and direct care staff. It was challenging to determine when and how to best access and engage palliative care services, as well as what setting would be most appropriate for consumers to reside in while receiving this care. For consumers, the residences are their homes, not just facilities where they receive care and support. Therefore, questions arise about whether it is appropriate to help fulfill individual

consumers' or family members' wishes to remain in their own home through end of life, while balancing this against consideration of how doing so might impact other residents.

In addition to end-of-life issues, CCNS management staff has faced a number of complex situations related to older consumers with intellectual and developmental disabilities retiring from long-term day program participation and the need to help them engage in less taxing leisure activities. According to state regulations, consumers must be involved in active treatment that includes participating in day programs or work-related activities. As such, residents throughout the network have been expected to get out of bed between 5:00 a.m. and 6:00 a.m. to prepare for the day's activities. Typically, consumers leave their residence to travel an hour or more to their day program or work site. Consumers then attend a full day of program or work (a billable program half-day is four hours and a full day is six or more hours of activities), after which they then make the reverse commute back home. Consumers then prepare for dinner and participate in community inclusion or other activities in the residence (active treatment) before retiring for the night—an exhausting day by anyone's standards, let alone for older, medically frail individuals.

As there is no mandatory retirement age, the decision to slow down and to reduce the number of days one attends a day program or goes to work has been a challenge for agency staff, who strive to honor each consumer's wishes while also meeting regulatory requirements. In several instances, older residents reached the point where they simply did not have the physical stamina or interest to continue attending day program or go to work every day. In the general population, older adults usually have the option of slowing down, retiring altogether, and planning for how and if they wish to engage in

postretirement leisure activities (Tedrick, 1997). In CCNS residential programs, astute staff members who recognize the complexities of normative aging must justify and advocate with regulatory reviewers for any decrease in the level of activities for older consumers. The scarcity of retirement options for aging consumers with intellectual and developmental disabilities is also problematic. Heller (1999) asserts that “there are few policies and supports that permit individuals with developmental disabilities to retire from programs or activities in which they have been involved and to move into other types of programs or activities” (p. 153).

The issues experienced by CCNS are not unique and in many respects have been anticipated by researchers and administrators in the disabilities arena for the past twenty-five years. For example, Roberto and Nelson (1989) conducted a survey to assess the concerns of service providers in both the older adult and disabilities networks related to serving a growing cohort of elderly persons with intellectual and developmental disabilities. The study found the following issues to be of concern: access and availability of services, increased financial burden to providers, inadequate accommodations or facilities, changing needs for staff training, and the appropriateness of programming.

Two decades have passed since Roberto and Nelson’s study was conducted. The issue however, continues to be of concern to those service providers who care for older people and it is the approach and extent to which these community service providers have made the necessary adaptations to their physical plants, programming, work force, and funding paradigms that will determine whether they will continue to have utility and maintain viability as valuable community resources. The continued growth of the number of older consumers with

intellectual and developmental disabilities has a multifaceted impact on agency administrators, nursing, clinical and direct care staff, as well as on caregivers, policy makers and the older consumers themselves. For those who work with any of these constituencies, it is beneficial that studies like this one bring to light bureaucratic impediments and other formidable barriers service providers face when implementing programs and adapting facilities, so that the problems can be addressed and the agencies better equipped to provide quality care for this growing cohort of aging consumers.

The next section describes the definition of older adult and intellectual and developmental disabilities, as well as the operational definitions associated with organizational complexity, size, and affiliation.

#### Definitions Associated with Study

##### Older adult.

*Age* and what is considered *old age* are relative concepts. The American Association of Retired Persons (AARP), the national membership organization for older adults, has established the age of fifty years for membership eligibility. Certainly, setting a generous benchmark for the age at which one is considered “old” has significant benefits for AARP, as it allows them to market their services to an even broader membership base. In the general population, however, people are considered old once they reach or surpass the ages of sixty to sixty-five. This is the age at which a majority of older adults are eligible for government entitlements and benefits such as Medicare and Social Security. However, “social norms are more likely to define an individual as ‘old’ once they reach age seventy or eighty years” (Doka & Lavin, 2003, p. 137).

Defining the chronological age at which an individual with intellectual and developmental disabilities is considered old is a bit more complicated. For example, persons with Down syndrome experience health-related disease and dementia at an earlier chronological age than the general population (Janicki, et al., 1999; World Health Organization, 2000). It is estimated that beginning at age forty, the number of persons with Down syndrome with dementia will double every five years until age sixty-five (Coppus, et al., 2006). Therefore, “a person with Down syndrome may exhibit age-related signs that would be evident in a nondisabled peer a decade later” (Doka & Lavin, 2003, p. 138). Earlier studies that compared older and younger persons with intellectual and developmental disabilities found that cognitive and functional declines were gradual until early adulthood (Adlin, 1993). Later longitudinal studies on the health of adults with intellectual and developmental disabilities found that functional decline occurred most dramatically after the age of seventy and approximated the health declines of the general aging population (Adlin, 1993). However, individuals with profound mental retardation and individuals with Down syndrome experience premature aging in their forties or fifties (World Health Organization, 2000). In addition, for persons with intellectual and developmental disabilities, aging may include vision loss, hearing loss, mobility impairments, reduced stamina, and problems with cognition (Janicki, et al., 2002). For the purpose of this study, the age at which a person with intellectual and developmental disabilities is defined as an “older adult” is age fifty, to take into account those individuals who experience an earlier onset of age-related declines.

### Intellectual disability.

The American Association on Intellectual and Developmental Disabilities, in its Definition, Classification, and Systems of Supports Manual, 10<sup>th</sup> edition (Luckasson, et al., 2002, p. 23), defines intellectual disability as:

A disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. The disability originates before the age of eighteen. The term “intellectual disability” covers the same population of individuals who were diagnosed previously with mental retardation in number, kind, level, type, and duration of the disability and the need for people with this disability for individualized services and supports. Furthermore, every individual who is or was eligible for a diagnosis of mental retardation is eligible for a diagnosis of intellectual disability.

Intellectual disability is the more recently preferred term, rather than “mentally retarded,” in that intellectual disability is more comprehensive and multidimensional. The new term takes into consideration a person’s functioning in his/her typical environment and allows for the assessment of adaptive behavior of individuals within both their typical and their atypical environments, while also looking at the interventions (support systems) necessary for life functioning (Schalock & Luckasson, 2004). Consequently, even though there have been a variety of labels to define persons with an intellectual disability, the term is used interchangeably with developmental disabilities and mental retardation throughout this dissertation. The term “mental retardation” is used only in its historical context or when referencing organizations that continue to be labeled as such.

Included in the proposed study will be organizations that serve adults over the age of fifty years who have been diagnosed with an intellectual disability and/or a developmental disability, the latter of which includes a decline in cognitive functioning *and* restrictions in at least two

major life activities<sup>1</sup>. These major life activities include the following: self-care, receptive and expressive language, mobility, self-direction, capacity for independent living, and economic self-sufficiency. Organizations participating in the study may serve intellectually disabled older adults with autism, cerebral palsy, a genetic developmental disability (such as Down syndrome, Fragile X, Phenylketonuria (PKU), Prader-Willi), or have a dual diagnosis (mental health diagnosis in addition to an intellectual disability), epilepsy, traumatic brain injury, or any other pervasive developmental disorder.

#### Aging in place.

Aging in place is a concept that provides the option for a person to remain in his or her current living situation, often by adapting the environment to fit the changing physical and social needs of the person (Bigby, 2004).

#### Organizational complexity.

Organizational complexity is defined as “the amount of differentiation that exists within different elements constituting the organization” (Dooley, 2002, p. 2). Included in the study sample will be organizations of varying complexities. For the purposes of this study, organizational characteristics will be proxies for organizational complexity and will include the following: multipurpose and single-purpose agencies; faith-based and secular organizations; medium-size and large-size organizations.

#### Single-purpose agency.

For the purposes of this study, a single-purpose agency is defined and operationalized as a not-for-profit agency that provides specialized services for only one population or purpose, such as

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<sup>1</sup> Major life activities as defined in section 102(8) of the Federal Developmental Disabilities Act.

persons with intellectual and developmental disabilities, irrespective of the variety of services and settings.

#### Multipurpose agency.

For the purposes of this study, a multipurpose agency is defined and operationalized as a not-for-profit generalist organization that provides services to persons with intellectual and developmental disabilities in addition to one or more additional populations such as mentally ill adults, foster families, homeless persons, formerly incarcerated individuals, older adults, children, etc., irrespective of the number of settings and types of services provided to these populations.

#### Faith-based agency.

For the purpose of this study, a faith-based agency is defined as one that is presently affiliated with a religious denomination or has a religious mission. However, the services the organization offers may not have religious content and the organization may serve individuals of faith or no faith. (Kramer, Nightingale, Trutko, Spaulding, & Barrow, 2002).

#### Secular agency.

For the purposes of this study, a secular agency is defined as one that has no present religious affiliation.

#### Medium-size agency.

For the purpose of this study, a midsize agency is defined as a nonprofit service organization with a total annual operating budget of more than \$5 million but less than \$35 million.

#### Large-size agency.

For the purpose of this study, a large-size agency is defined as a nonprofit service organization with a total annual operating budget of \$35 million or greater.

### Residential services.

The organizations participating in this study are voluntary not-for-profit organizations licensed by the New York State Department of Health to provide housing and related services.

Residential settings include supervised group living (twenty-four-hour staffing and supervision), as well as semi-independent or “supported” group living (a home with less than twenty-four-hour staffing and supervision for two or more individuals). Group homes for persons with intellectual and developmental disabilities may include Community Residences (CRs), Intermediate Care Facilities (ICF-DDs), and Individual Residential Alternatives (IRAs).

### Intermediate Care Facility (ICF-MR).

An institution that houses four or more individuals with developmental disabilities or a related condition and has as its primary purpose the diagnosis, treatment, or rehabilitation of the individuals, and provides ongoing evaluation, planning and twenty-four-hour supervision, coordination, and integration of health or rehabilitation services to help the individual function at their optimal capacity (42 Code of Federal Regulations (CFR) 435.1009).<sup>1</sup>

### Individual Residential Alternative (IRA).

A supervised IRA is a residence that provides room and board as well as residential habilitation services. This includes assistance with acquisition, retention, or improvements of self-help skills related to activities of daily living and the social and adaptive skills necessary to enable individuals to reside in a noninstitutional setting. Comparatively, Supported IRAs are apartments that house two or more individuals with less than twenty-four hour staffing (OPWDD – 2009).

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<sup>1</sup> The acronym ICF-DD is also used in place of ICF-MR throughout this dissertation. However, the federal code of regulations continues to use ICF-MR.

The graying of older adults is a relatively new phenomenon resulting in part from medical and technological advances, as well as the ways society has evolved its views of older adults and how they should be cared for. The following chapter provides the historical context regarding the treatment for disabled individuals from the nineteenth century through the present day.

## Chapter II. Historical Overview

## Role of Almshouses for the Poor

Almshouses for the Poor played a prominent role in the nineteenth century in domiciling and treating “idiots” who were the idle poor, deemed unable to be self-sufficient. According to Ferguson (2004), a survey published in 1857 noted that 5.5 percent of individuals living in almshouses in New York were labeled “idiots” and 16.6 percent were labeled “lunatics.” These idiots were treated harshly; “the notorious ‘crazy cellars’ or dungeons held these poor souls: naked, chained, without heat or light” (Ferguson, 2004, p. 40).. In 1844, Dorothea Dix, an advocate and spokesperson for the disabled, petitioned legislators in New York to create state asylums that would provide custodial care to incurable and mentally deficient individuals (Ferguson, 2004). The mid-nineteenth century saw the opening of state “training schools” to educate and train children with the intent that these individuals would be returned to their families and become productive members of society. The first training school for children with mental retardation was the Perkins Institute in Boston, founded in 1848 (DeWeaver, 1983).

Coinciding with the great wave of immigration (1890–1920) and the criminalization of the “feble-minded,” the number of institutions providing custodial care to poor immigrant individuals with mental retardation grew as a way to protect society from those individuals who were deemed violent and derelict. “Instead of viewing children as potential victims of their immoral surroundings, the children were labeled ‘mental defectives’ who threatened society by their inherent immorality; society assumed they would likely reproduce (unlike those with more severe mental retardation) unless they were *controlled*” (Metzel, 2004, p. 425). Farm “colonies” were developed, and the asylees worked the land to help defray the cost of their care

(Ferguson, 2004). Therefore, there was an emphasis on isolating these “mental defectives,” which is in stark contrast to the more contemporary philosophy of community integration.

### Compulsory Education and the Eugenics Movement

Beginning in 1900, compulsory education for persons with mental retardation was considered one of the first community services offered to these individuals (Wolfensberger, 1975). The first schools built for the mentally retarded were intended to educate and socialize defective children and then return them to their families. These schools were not to be considered permanent homes and were meant for only those children who were educable or mildly retarded, not for children who had multiple handicaps, were grossly deformed, or were mentally ill (Wolfensberger, 1975).

Upper class families<sup>1</sup> cared for their “mentally defective” children at home with hired help, while the middle class, who had limited options, sent children away to be cared for in institutions alongside poorer immigrant children (Metzel, 2004). It was during this time that the eugenics movement began to define what was wrong with society, and the mentally retarded were increasingly victimized by the growing acceptance of this movement. Mackelprang and Salsgiver (1996), in describing eugenics, wrote, “People with disabilities were prevented from marrying or from having children for fear of propagating their imperfections” (Mackelprang & Salsgiver, p. 9). The belief was that mental, physical, and character defects were hereditary, and feeble-minded or defective parents gave birth to feeble-minded, criminal, defective pauper children. Since defective parents or families were not capable, the responsibility therefore rested with the state.

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<sup>1</sup> Rosemary Kennedy, sister of President John F. Kennedy, is an example of an upper-class “mental defective” who was cared for at home.

Involuntary sterilization became popular in 1907, when Indiana passed a law requiring the sterilization of criminals and “feeble-minded” individuals living in institutions. Several states followed suit by passing laws mandating sterilization. Parallels existed between the eugenics movement in the United States and the Nazi eugenics programs. In the words of Harry Laughlin, a sympathizer with Nazi science programs, respected American scientist, and proponent of sterilization (as cited in Noll & Trent, 2004):

For the social care and eugenical control of such families different methods have been proposed. Among these should be named segregation, which proposes to institutionalize all feeble-minded persons of a definitely low degree, within the state....Segregation has the double advantage of taking care of the individual, eugenically, that is, in preventing his reproduction, and at the same time, in caring for him as a socially incompetent individual. (Noll & Trent, 2004, p. 226)

Another method of controlling the heredity of defective individuals was through reproductive sterilization, and according to Laughlin:

Welfare and charity demand that a person once born be given every opportunity and aid to live and to have a chance to develop and to enjoy the most that is in him. While eugenics agrees to this proposition, social welfare agencies must also agree to the eugenical principle that only those persons best endowed with superior mental, physical, and temperamental hereditary qualities should be permitted to reproduce, and thus serve as seed-stock for the next generation. (Noll & Trent, 2004, p. 228)

Segregation and sterilization continued as the predominant themes from the turn of the century until the early 1940s, when eugenic programs fell out of favor. In World War II, some of the so-called mental defectives were integrated into the military to do menial jobs and free up “normal” soldiers to engage in combat or more complicated military duties (Gelb, 2004). When the war was over, “the retarded were again seen as marginal members of the work force and their purported differences from “normals” once more assumed their prewar salience” (Gelb, 2004, p. 316).

## Parent Movement

After World War II ended, there was a proliferation of community groups formed by white middle-class parents of individuals with mental retardation. These parent groups formed organizations to educate their children, who were typically excluded from regular classrooms in public schools (Metzel, 2004). It was during the 1950s that organizations such as the Association for the Help of Retarded Children (AHRC) and the National Association for Retarded Children (presently known as the ARC) were formed. These organizations formed local affiliate agencies in cities across the country to give voice to the growing number of concerned parent groups. It was the parent groups that succeeded in changing the public image of, and discussion about, what it meant to be mentally retarded and how society should view the issue “as a social problem faced by ordinary Americans—which, for the most part, meant middle class and white” (Castles, 2004, p. 355). Through their coordinated efforts, parent advocates made progress in alleviating the shame and isolation family members experienced when they had a mentally retarded family member. These attitudinal changes led to the acceptance of mildly retarded children into special education classes in public schools and eventual acceptance of mildly mentally retarded individuals into other mainstream venues in the community such as organized sports, cultural events, religious and medical institutions (Castles, 2004).

## Federal Funding of Support Services for the Mentally Retarded

Despite the parent movement and the successes relative to changing attitudinal barriers to better integration of the mentally retarded into public education and the

community, the twenty-year period from 1950 to 1970 saw the greatest increase in the number of state institutions built to meet the growing demand for placement.

In the mid-1950s, the Children's Bureau provided federal funding to establish child development centers throughout the country that would serve children with mental retardation and their families (Nehring, 2004). The Children's Bureau was also responsible for developing and disseminating educational materials, training medical and nursing professionals about mental retardation, conducting research, and identifying and documenting the unique needs of this population (Nehring, 2004).

In 1961, President John F. Kennedy, sensitized to the issue by his familial situation, formed the President's Panel on Mental Retardation. The panel made recommendations for the establishment of State Planning Councils that would study the needs of the mentally retarded and make recommendations to facilitate the coordination of services for this population. The growing wait lists for state institutions led to the passing of the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 (P.L. 88-164). This legislation created university centers that provided education, research, and services to persons with mental retardation and their families (Nehring, 2004; Metzel, 2004). While this legislation provided capital funding to states for construction of institutional facilities, the conservative members of Congress, bending to the strong lobby of the prevailing medical establishment, would not approve the appropriation of funds necessary to staff and operate these centers (Levine, 1981). According to Cutler, et al., 2003, "anything that smacked of 'socialized medicine' was still pretty taboo at a time when anticommunism was so much a fact of life" (Cutler, 2003, p. 385). After the assassination of Kennedy, Lyndon B. Johnson became president

and his administration adopted JFK's civil rights agenda. In August 1965, after capturing the presidency in a landslide election, and with a Democratic majority in the legislature, Johnson, adept at political maneuvering, finally secured the necessary votes to pass amendments (Community Mental Health Centers Act, P.L. 89-105) that would appropriate the funds necessary to staff community health centers (Levine, 1981)..“It was generally felt at the time that passing the staff portion of the Mental Health Act was to a large extent accomplished out of sentiment for President Kennedy” (Cutler, 2003, p. 385). These community health initiatives, as well as the Great Society Programs, Medicare, Supplemental Social Security Income (SSI), and Medicaid, set the foundation for the move from institutional care for the mentally ill and mentally retarded to less restrictive community-based services and programs. Medicaid provided the financial mechanism for states to leverage federal money to care for persons with mental retardation through developing Intermediate Care Facilities –Mentally Retarded (ICF-MRs), which were community-based residences that provided care more economically than in a skilled nursing facility (Gettings, 2011).

#### Deinstitutionalization Movement—1970s

Although the federal government made strides in establishing a community-based infrastructure to deal with public health issues and disseminate information for the mentally retarded and their families, government failed to provide even a minimally acceptable level of care for mentally retarded individuals living in state-operated institutions. The less than satisfactory conditions of overcrowded and understaffed institutions (conditions that were chronicled by the media) were just some of the antecedents that led the push to move residents

out of large institutions that provided, at best, custodial care into smaller, community-based settings (DeWeaver, 1983). Several other marginalized groups such as the elderly, mentally disabled, criminals, and children were warehoused in large institutional settings. In addition to the pressure of being in the media spotlight, deinstitutionalization gained traction because of other advances at the time, including the advancement of civil rights, the greater use and efficacy of psychotropic medications, the proliferation of residential alternatives by the nonprofit sector made possible through financial subsidies from state and legislative actions, and the successful advocacy of parent groups (Doka & Lavin, 2003; Metzel, 2004; Segal, 1995). Piggybacking on the relocation of the mentally ill population into community-based programs, persons with mental retardation were also moved to settings that were more appropriate.

According to Wolfensberger (1974), the concepts that framed the deinstitutionalization movement were “normalization” and “the least restrictive environment.” The principle of normalization means to approximate the life and opportunities afforded to nondisabled individuals, including being seamlessly integrated into the fabric of the community (Wolfensberger, 1974). The concept of least restrictive environment emanated from the court decision *Wyatt v. Stickney* (1972), which states: “No person shall be admitted to the institution unless prior determination shall have been made that residence in the institution is the least restrictive habilitation setting” (DeWeaver, 1983, p. 436). Today, the concepts of normalization and the least restrictive environment continue to drive the service model for offering community-based care to persons with intellectual and developmental disabilities.

### Willowbrook Consent Decree

In New York State, deinstitutionalization of the mentally retarded into smaller group home settings was further prompted by the state's response to one of its largest institutions, Willowbrook State School. In 1965, Robert Kennedy, senator from New York, visited Willowbrook, where he witnessed the overcrowded and deplorable conditions at the facility. Senator Kennedy publicly declared the campus "a snake pit" and called for systemic reform in state facilities. Conditions at Willowbrook and other New York State institutions persisted until 1972, when Geraldo Rivera, a news journalist, paid an unannounced visit with camera crew in tow, exposing to the public the abuse and neglect of thousands of individuals who were left in squalor in the back wards of the institution. A lawsuit was filed on behalf of the residents of Willowbrook against New York State in 1972 for failure to provide basic care and treatment to the individuals in their care. A settlement was reached: The *Willowbrook Consent Decree* (1975) established the Office of Mental Retardation and Disabilities (OMRDD)<sup>1</sup> and facilitated the movement of Willowbrook residents, as well as twenty-two thousand individuals in twenty-five other large state institutions that housed the mentally retarded, into much smaller group homes in the community (Gettings, 2011).

The shift from institutional to community-based services that began with Willowbrook continued at a fast pace through the 1980s and 1990s. During the period, New York closed its largest and most prominent institutions: Craig, Westchester, Rome, Newark, Letchworth, and Syracuse. Aiding the shift was federal approval in 1991 of a plan that allowed New York to use Medicaid funds for community-based services. (Rothman & Rothman, 2004, p. 446)

The plan referenced above is financed by Medicaid, Section 1915(c) of the Social Security Act, which established the home and community-based waiver authority. The importance of this

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<sup>1</sup> OMRDD name changed in 2010 to Office of Persons with Developmental Disabilities (OPWDD).

action cannot be overestimated. It was crucial to the proliferation and development of community-based programs that continue today.

### Changes in Models of Care from Institutional to Community Care

States have long since shifted their service delivery for persons with intellectual and developmental disabilities from large-scale institutional models to more community-based residential and long-term care models. During the past thirty years, a large number of state-sponsored institutions were downsized and persons with intellectual and developmental disabilities moved into congregate homes in the community (Martinson & Stone, 1993). The Omnibus Reconciliation Act of 1981 allowed for Medicaid funding establishing the Intermediate Care Facility—Mentally Retarded (ICF-MR) for those qualifying for nursing home level of care as well as financing for the Home and Community-Based Services (HCBS)<sup>1</sup> Waiver program, which Congress authorized in the early 1990s (Lightfoot, 2007). This funding served as a catalyst for the development of the extensive community-based disability network in New York City, a network designed to accommodate the residential and service needs of persons with intellectual and developmental disabilities.

The shift from the provision of residential services in large institutional settings to the utilization of smaller community-based group homes is illustrated by the following statistics: in 1977, 26,552 persons with intellectual and developmental disabilities in New York State resided

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<sup>1</sup> In 2010, approved waiver services in New York State, under Section 1915 (c) of SSA, included a flexible array of services and supports funded by Medicaid that include residential and community rehabilitation, day habilitation, prevocational services, supportive employment, respite services, environmental modifications, adaptive equipment, plan of care support services, family education and training, and consolidated supports and services (OPWDD, 2010). Retrieved April 16, 2010, from <http://www.omr.state.ny.us/ws/servlets/WsnavigationsServlet>.

in group homes and 18,446 persons with intellectual and developmental disabilities lived in large state institutions. Comparatively, in 2009, there were 62,438 persons with intellectual and developmental disabilities living in group homes in New York State and only 2,154 lived in state institutions (Braddock, 2011).

The change in relative size of residences over the past three decades is also quite dramatic. In 1977, 80 percent of the total number of persons with intellectual and developmental disabilities institutionalized in New York lived in settings with sixteen or more residents compared to only 7 percent in 2006. In 2006, 93 percent of group homes in New York State have fifteen or fewer residents (Prouty, Lakin & Bruininks, 2007). Despite the proliferation of group homes in the community over the past thirty years, in 2006 there were 84,523 individuals reported to be on wait lists for residential services nationwide (Alba, et al., 2007). In New York State, 4,201 individuals were on wait lists for residential services in 2010 (Braddock, 2011). As several states do not keep wait lists, the need is most likely greater than reported (Braddock, 1998). Nonetheless, there is clearly a tremendous gap in the documented need for residential care and the availability of these residential opportunities in New York State and throughout the country.

While there continue to be a significant number of individuals who reside in group homes, an even larger number of persons with intellectual and developmental disabilities live in the community with their parents or other relatives (Doka & Lavin, 2003; Janicki & Ansello, 2000). It is estimated that, nationally, 1.9 million persons with intellectual and developmental disabilities, of whom 25 percent are age sixty or older, live alone or with a family caregiver (Baxley, Janicki, McCallion & Zendell, 2003). In New York State, 27 percent of caregivers (44,237) are over the age of sixty (Braddock, 2011), thereby reinforcing the need for creative

responses to address the service needs of aging adults with intellectual and developmental disabilities living in the community, and of their caregivers.

#### Inclusion Models and Family Supports: 1990s to Present

The 1990s saw the emergence of new approaches to models of service delivery, which fostered full participation and integration of individuals with disabilities into the community. Community inclusion is a guiding principle that emerged from the principles of “normalization” mentioned earlier and the concept of “least restrictive environment” (DeWeaver, 1983, p.436). Inclusion for persons of all ages and disabilities allows for full accessibility and participation of these individuals in the community.

One such model is *empowerment*, which is based on the premise that consumers, their families and/or caregivers should be in control of the decisions and choices that impact on their lives. This model assumes that consumers, however limited in their functional capacity, have aspirations and preferences and, as such, are experts about their own lives. Building on the strengths of consumers as well as their family and community resources, older adults with disabilities are deemed to have an inherent right to make choices about the types of services they want and from whom they will receive those services (Goldmeier & Herr, 1999).

According to Heller (1999), the community inclusion and empowerment models emphasize both the consumer’s right to choice and the responsibility of society to provide the necessary supports to help persons with intellectual and developmental disabilities function and be integrated to the greatest extent possible into the community. Service delivery within the community inclusion model incorporates the following elements: “greater commitment to community and family resources; emphasis on human relationships and friendship;

individualized life plans and person-centered programming; choice and control by people with disabilities; and an emphasis on quality of life” (Heller, 1999, p. 150). A person-centered approach, the norm in the developmental disabilities arena, incorporates consumer preference and builds upon the strengths inherent in the formal and informal environments of the person and of the organization.

According to Bradley (2000), the success of community inclusion models depends on the following three components: self-determination, maximizing the supports of the person’s informal network, and the coordinating role of service brokers. The most salient feature of this flexible model includes the development of “individually controlled budgets that can be dispersed based on an agreed-on person-driven model” (Bradley, 2000, p. 192). Examples of these initiatives include the Cash and Counseling Programs and the Self-Determination Initiative, both sponsored by the Robert Wood Johnson Foundation, which are described in more detail in the following chapter. These demonstration programs provided cash grants to elderly and disabled persons along with information regarding available resources and assistance with care coordination. Several states incorporated these demonstration models as part of the Home and Community Based Medicaid Waiver program for community-based long-term care (Bradley, 2000). In 2006, 54,251 persons with intellectual and developmental disabilities residing in communities in New York State received services as part of the home and community based services 1915(c) Medicaid Waiver program (Lakin, Prouty & Coucouvanis, 2007), and by 2010, the number of individuals expanded to 71,000 (D. Frescatore, personal communication, September 14, 2010).

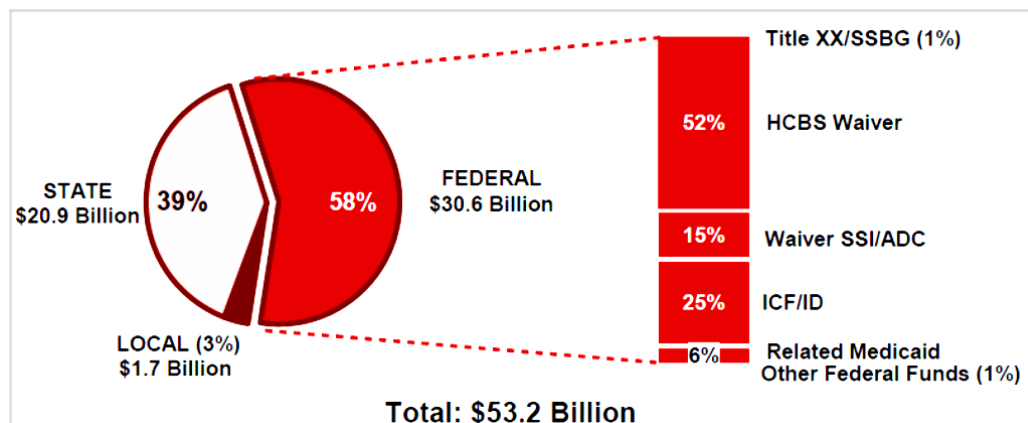
Service models that emphasize cost containment, flexibility, and person-centered planning are best incorporated in the more contemporary Family Support Program models. One such

family support model includes Futures Planning, which assists caregivers with planning for the future needs of the adult disabled family member. With the assistance of a care manager, family members, along with the individual with a disability, prioritize goals relating to the future care of the individual. The care manager subsequently assists the individual and their family caregivers to gain access to services provided by mental health, health care, legal, disabilities or private care networks (Lavin & Doka, 1999). Family Support Program models include a cash subsidy to families who then purchase needed services on behalf of the individual (Braddock, 2011).

#### Financial Models to Support Care

Funding to support care for persons with intellectual and developmental disabilities comes from federal Medicaid appropriations, state and municipal matching funds and local unmatched funds. Unmatched funds consist of local government funds that do not leverage federal Medicaid funds (Rizzolo, Hemp, Braddock, & Pomeranz-Essley, 2004). Nationwide, in 2009, \$53.2 billion was spent on community services, of which \$30.6 billion was federal revenue, \$20.9 billion was state revenue, and \$1.7 billion was local revenue, as shown in Figure 1.

*Figure 1*  
United States trend in revenue source in fiscal year 2009

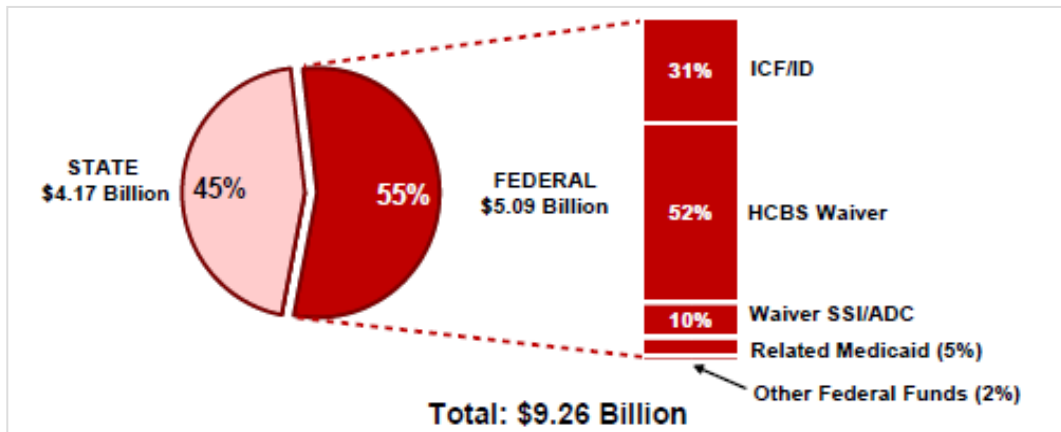


Note. Figure 1 and Figure 2 from Coleman Institute and Department of Psychiatry. University of Colorado, 2012. Braddock, et al. (2011). Reprinted with permission.

In 2009, total New York State revenue for community services for the intellectually disabled population was \$9.26 billion, of which \$5.09 billion was federal revenue and \$4.17 billion was state revenue, as shown in Figure 2. New York had the highest allocation of state revenue allocated for community services for the intellectually disabled than any other state in the country, attesting to its generous support and commitment to provide a robust network of programs to serve the intellectually disabled (Braddock, 2011).

Figure 2.

New York State trend in revenue source in fiscal year 2009



Nationally, the average annual cost of care in 2002 for a resident living in a private ICF-DD for fifteen or fewer persons was \$72,460, according to financial data collected from thirty-five states (Rizzolo, et al., 2004). That same year, the average annual cost of care for a New York State resident living in a private ICF-DD for fifteen or fewer persons was \$102,508, and the cost per participant in the Home and Community-Based Services Waiver Program was \$48,748. In 2002, spending for home and community-based waiver services represented 44 percent of the total spending in New York State for persons with intellectual and developmental disabilities (Rizzolo, et al., 2004) as compared to 52 percent of total spending in 2009 (Braddock, 2011); this represents an increase of 8 percent.

The federal allocation of funding for community services for persons with intellectual and developmental disabilities increased from 23 percent in 1977 to 50 percent by 2002. In fiscal year 2002, 60 percent of spending for the persons with intellectual and developmental

disabilities in New York State, was allocated for community services, for both individual and family support programs, including supportive employment, supported living, personal assistance, respite care, family counseling, behavior management services, in-home environmental modifications, and in-home training (Rizzolo, et al., 2004). The national average family support spending per family for these services was \$3,440 in fiscal year 2002 (Rizzolo, et al., 2004), and \$3,762 in 2009 (Braddock, 2011), representing an increase of 8.5 percent.

Given the cost benefits of providing long-term care in a community as opposed to an institutional setting, as well as providing community care as opposed to residential care administered by the state or a voluntary agency, the potential for growth is obviously in the HCBS waiver program, despite the long wait lists for residential placements. HCBS waiver services provide a menu of options, including personal care that helps maintain persons of all ages in the community who would otherwise be eligible for nursing home care.

Another way to serve the population of older adults with intellectual and developmental disabilities cost effectively is by accessing services from the generic older adult network. Significant policy and legislation enacted over the past several decades have attempted to bridge some of the bureaucratic schisms between the intellectual and developmental disabilities and the aging networks in addition to setting the policy framework, which also values providing services to older adults in a least restrictive environment. The next section discusses important legislation and policy decisions that helped to establish the disabilities and older adult service networks in New York State as well as the government's response to the treatment and care for older adults.

## Relevant Policy and Legislation

The treatment and care of individuals with disabilities and older adults have been the byproducts of policy and court decisions. The spectrum of care over the past two centuries, from housing disabled individuals in almshouses for the poor through the current model of care in small-scale group homes or community settings, has evolved within the historical context, reflecting the ideology of the time. This section briefly describes the important policy and legislative decisions that have affected older adults in general and individuals with disabilities in particular.

The industrialization of the U.S. economy during the twentieth century weakened the extended family network. Consequently, the lack of economic security of the aged, sick, and disabled became a significant problem, which was further fueled by the economic hardships experienced during and following the Great Depression. In 1934, President Franklin D. Roosevelt formed a committee to study the problem of economic security and to make recommendations on how the legislature might deal with this challenging problem. Based upon the committee's recommendations, the **Social Security Act of 1935, P.L. 74-271** was enacted to provide ongoing retirement income for workers when they reached the age of sixty-five (DiNitto, 2003). In 1939, the Social Security Act was amended to include payments to the spouse and minor children of retired workers (dependent benefits) and survivor benefits in the event of the premature death of a working spouse.

As the country entered a period of economic growth and prosperity post-World War II, the prevailing democratic ideology that valued economic opportunity and human rights for

all resulted in an expansion of the modern welfare state anchored in a strong family orientation.

In 1956, the Social Security Act was amended to expand benefits for persons who had served in the armed forces, disabled workers ages fifty to sixty-five years, and disabled adult children. Shortly thereafter benefits expanded to include full benefits at age sixty-two for women who were widowed or parents with dependent children.

The **1956 amendments to the Social Security Act** took on a family orientation, and states were encouraged to grant assistance and “other services” to needy children, parents, and relatives to help “maintain and strengthen family life.” The 1958 and 1962 amendments to the Social Security Act further strengthen this orientation (Gilbert & Terrell, 2002, p. 203).

**Title XX amendments to the Social Security Act of 1935** were enacted in 1962 and provided aid to states for social services to help needy adults and families from becoming dependent on welfare benefits. The amendments also increased the federal portion of the funding ratio of welfare benefits to 75 percent, and authorized states to contract with private vendors for the provision of social services. In 1965, during the tenure of President Lyndon B. Johnson, the **Medicare (Title XVIII)** and **Medicaid Bills (Title XIX)** amendments to the Social Security Act of 1935 were enacted which created health insurance benefits for Social Security beneficiaries age sixty-five and older (Gettings, 2011).

In 1972, under President Richard Nixon, the Social Security Act of 1935 was amended to create the **Supplemental Security Income (SSI) program**. SSI provided cash benefits to low-income elderly, blind, and disabled. SSI income is below the federal poverty level. Therefore, SSI recipients are also eligible for Medicaid. As mentioned earlier, Medicaid funding allowed states to establish community residences and day

programs for individuals with developmental disabilities throughout the 1960s and 1970s (Rizzolo, Hemp & Braddock, 2004).

The 1972 amendments to the Social Security Act “also added as optional Medicaid-covered services under state plans for intermediate care facilities for the mentally retarded (ICF-MR) and day services as well as inpatient psychiatric services. Residents of ICF-MRs and the disabled, in general, are among the most expensive groups in Medicaid” (Klemm, 2000, p.107). These amendments also expanded Medicare coverage for adults with disabilities receiving Social Security benefits (Braddock and Hemp, 2003).

The Reagan Era’s **Omnibus Reconciliation Act of 1981 (P.L. 100- 203)** mandated the diversion of persons with developmental disabilities from nursing homes (Anderson, 1993). The Omnibus Reconciliation Act also authorized the Social Service Block Grant (P.L. 97-35)<sup>1</sup> and the Medicaid Home and Community-Based Services Waiver, as a means for reducing federal spending on health care and welfare spending by granting the state budgetary authority (Rizzolo, et al., 2004). In Rizzolo, et al. (2004), the conclusion reached was that:

The HCBS Waiver has now emerged as the principal Medicaid program underwriting MR/DD long-term care, surpassing Medicaid ICF/MR spending in the states in 2001. The Waiver provides federal reimbursement for a wide array of community supports. These include habilitation training, respite care and other family support, case management, supported employment, supportive living, various professional therapies, assistive technology, behavior management, and a number of other types of assistance in home-like community based environments. No state financed all of these options, and there was considerable variability in the services that states opted to fund via the Waiver. The Medicaid Waiver, unlike the ICF/MR program, is a

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<sup>1</sup> Block grant funding allows states flexibility in what types of services they will provide and to what extent they will provide them.

financing vehicle and not a distinct, standardized program. (Rizzolo, et al., 2004, p. 10)

**Section 1115 waivers** provide a CMS-approved mechanism that provides regulatory relief and grants states flexibility in Medicaid programs, to test innovative programming models that provide its beneficiaries with more efficient and cost-effective supports and services. The Medicaid Waiver program funds an array of community-based medical supports and service programs in New York for older adults, the disabled, the mentally ill, and other special populations with chronic care needs with health care, personal care, long-term care, care coordination, and other services. The Medicaid Waiver program continues to support OPWDD-funded programs in New York and the number and types of services funded under the waiver continue to expand. For example, New York State OPWDD's 2010 through 2014 waiver renewal expanded the service options to include intensive behavioral services, community habilitation, pathways to employment, community transition services, and self-directed service options.

**The Older Americans Act of 1965 (P.L. 89-73)** was another significant civil rights accomplishment of President Johnson's administration, built on the foundation provided by the Kennedy presidency. Community-based services and programs for the general population of older adults were a consequence of this federal legislation. The Older Americans Act funded services that promoted the health, independence, and functional ability of the general population of older adults. Title III of the Older Americans Act mandated the establishment of the Administration on Aging at the federal level, a State Office on Aging in every state and multiple Area Agencies on Aging (AAAs) that have program oversight at the local community-based level (Putnam, 2007). The Area Agencies on Aging essentially serve as the administrators of funding, and as is the case

outside of New York City, they often are the direct providers of senior centers, nutrition sites, and in-home services. Title IV of the Older Americans Act funded education and provided the impetus to establish university-based centers to serve individuals with disabilities. The 1987 amendment of the Older Americans Act (P.L. 100-175) mandated better integration of services provided by the generic older adult network and the disabilities network (Bigby, 2004). In 1989, this integration and coordination was codified in a Memorandum of Understanding (MOU) between the Administration on Aging (AOA) and the Administration on Developmental Disabilities (ADD). The MOU was intended to facilitate service coordination to address the needs of older adults with intellectual and developmental disabilities and to integrate older adults with intellectual and developmental disabilities into generic programs for older adults such as senior centers, nutrition programs, and adult day care (Kultigen & Romancer, 1993). The 1992 amendments to the Older Americans Act, P.L. 102-375, expanded the role of AAAs by directing them to include outreach and the provision of services to older adults with intellectual and developmental disabilities and their aging caregivers (Hacker, McCallion & Janicki, 2000). This development set the stage for a number of demonstration projects that were carried out across the country.

This legislation was important for older adults of all functional abilities and, as such, intellectually disabled individuals have opportunities to participate in services established through funding under this legislative act. The act established an important silo of government bureaucracy that serves adults of all abilities.

**The 1975 Developmental Disabilities Assistance and Bill of Rights Act, P.L. 93-112**, provided the policy framework for the establishment of university-based

consortiums consisting of researchers from the rehabilitation, developmental disabilities, and aging fields.

The 1984 amendments to the **Developmental Disabilities Assistance and Bill of Rights Act, P.L. 98-527**, required that each state have a three-year state plan for developmental disabilities issued by the governor and the state's disability planning council (Janicki, Knox & Jacobson, 1985). Since that time, both the New York State Office of Persons with Developmental Disabilities (OPWDD) and the New York State Office for the Aging (SOFA) have sponsored several demonstration projects (described later in this chapter), have developed educational materials on aging and intellectual and developmental disabilities, and have formed coalitions to foster integration across service networks (McCallion & Janicki, 1997; LePore & Janicki, 1990).

**The 1990 Americans with Disabilities Act, P.L. 101-336, (ADA)** prohibited discrimination against individuals with disabilities in the provision of goods and services, travel, housing, employment, and public accommodations and other amenities enjoyed by the greater public, and required the elimination of barriers to access at social service centers, senior centers, and day centers. In New York, many social service programs and residential programs predate the passage of ADA and therefore may not have to comply fully with ADA regulations, unlike residences and program facilities established after this legislation.

The 1999 Supreme Court Decision in *Olmstead v. L.C. and E.W.* (119 S.Ct. 2176; 527 U.S. 581) related to a case of two women with mental impairments who remained institutionalized despite professional assessment that they could live independently in the community with supports, had they been available. The decision held that the

unnecessary segregation or “unjustified isolation of individuals with disabilities is properly regarded as discrimination based on disability.” The court ruling directed that states comply with the ADA mandate to provide services to qualified individuals in the *most integrated setting* appropriate to need.

A 2001 executive order, the **New Freedom Initiative**, directed federal agencies to adhere to the Olmstead decision. The order also called for the establishment of state-based demonstration programs called **Aging and Disability Resource Centers (ADRCs)** to be implemented by the Administration on Aging (AOA), an agency of the Department of Health and Human Services. ADRCs provide one-stop-shops or single points of entry for older persons with disabilities seeking community services and support (Putnam, 2007).<sup>1</sup> Other legislative initiatives that grew out of the New Freedom Initiative were incorporated into the 2006 amendments to the Older Americans Act. These amendments were designed “to foster opportunities for people with disabilities that allowed the Centers for Medicare and Medicaid Services (CMS) to give states greater opportunities to pursue all sorts of strategies and to pilot innovative ways for service delivery. Following are some of the programs that resulted: Money Follows the Person and Cash and Counseling, both sponsored by CMS; and Evidence Based Health, Wellness and Prevention programs; Nursing Home Diversion grants; and Alzheimer’s Disease Development Grants to States, all sponsored by AOA” (Browdie, 2008, p. 78). Other initiatives fostering better integration across service networks include New York State’s **Most Integrated Setting Coordinating Council (MISCC)** that has in its statute a directive to “address cross-systems issues that create roadblocks to community

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<sup>1</sup> New York State ADRC is called NY Connects: Choices for Long Term Care. New York City, however, is currently not part of NY Connects.

integration” as well as to “support the closure of OMRDD’s developmental centers and moving those people into the community, as is the goal of the Olmstead Act” (OMRDD Press Release, July 7, 2009).

More recently, OPWDD submitted applications to CMS to expand service options under 1915(b) and 1915(c) sections of the home and community-based waiver authority. OPWDD’s **People First Waiver** initiates the development of Developmental Disabilities Individual Support and Care Coordination Integrative Care and Service Options (DISCOs). DISCOs will function as fiscal intermediaries responsible for integrating care across all supports and services. Within the framework established for special needs populations under recent initiatives in health care reform, DISCOs will function as managed care entities for special needs populations that, for a fixed fee, will be responsible for coordinating all or a portion of supports and services. The per-member-per-month (PMPM) payment will cover primary, specialty, and acute medical care, adult day care, Article 16 clinical services, behavioral health care, home health care, personal care, nursing home, residential care, respite, rehabilitation, day services, home delivered meals, transportation, and durable medical equipment (The Scan Foundation, 2011). Voluntary service providers throughout New York have begun to form coalitions with the intent of positioning their response to a Request for Application (RFA), scheduled to be released by OPWDD in the spring of 2013, which will operationalize components of the DISCO model.

By expanding Medicaid waiver service options, OPWDD hopes to expand the capacity of the provider network to respond to the service needs of the growing number of older adults with intellectual and developmental disabilities that require care. Since

the Center for Medicaid and Medicare (CMS) will only approve budget neutral proposals under the waiver authority, expanding capacity will be accomplished solely through cost-cutting measures (OPWDD, 2012). The policy shift in Medicaid programs is consistent with the Olmstead Decision and the Americans with Disabilities Act, as well as the **Patient Portability and Affordable Care Act, P.L. 111- 148 (PPACA)**, which President Barack Obama signed on March 23, 2010, in that they support the “most integrated setting” for those with disabilities and chronic health conditions. The goals of PPACA will be achieved, in part, through incentivizing states to adopt innovative projects that foster integration, provide quality care, and achieve better health outcomes. Opportunities under PPACA, which will be phased in beginning January 2014, incorporate the following provisions:

- Expand the number of Americans insured for health care;
- Provide health coverage for those with preexisting medical conditions;
- Establish care coordination—a pivotal role to an integrated health system;
- Employ technology such as electronic health records to foster communication among providers;
- Improve treatment and monitoring of co-occurring disorders and those with chronic conditions;
- Focus on wellness and preventive care;
- Track quality outcomes with goals of reducing number of hospitalizations and emergency room visits; and
- Incentivize payment methodology based on outcomes through risk-sharing methods as well as a shared saving.

The Patient Protection and Affordable Care Act expands HCBS waiver options to include incentives for states that institute fully integrated Medicaid long-term care programs for beneficiaries who are dually eligible (aka *duals*) for both Medicaid and Medicare. Medicaid long-term care users “are individuals with disabilities who require access to personal care services and durable medical equipment, and they are seniors who need assistance with activities of daily living in their homes or in a nursing facility” (Kaiser, 2001, p. 4). Medicaid long-term care spending accounts make up 6 percent of all Medicaid enrollees. However, in 2009, they accounted for more than half (52 percent) of all Medicaid expenditures (Kaiser Family Foundation, 2011). To control escalating Medicaid health care expenditures, it is imperative that states do a better job of integrating health care and community support services for older persons with intellectual and developmental disabilities. The next chapter differentiates the orientation and functions of the lead regulatory and funding agencies for older adults and for the people who are intellectually disabled in New York State. Described are the outcomes of select demonstration projects that attempted to bridge the divide between the older adult and the disabilities service networks.

### Chapter III. Integration of Aging and Disabilities Networks

There have been a number of attempts in the past several decades to integrate persons with intellectual and developmental disabilities into programs that serve the general populations of older adults, such as senior centers and adult day programs for persons with dementia. These early demonstration projects were collaborative efforts of Area Agencies on Aging (AAAs) and State Offices for Mental Retardation and Developmental Disabilities. Integrating services across networks with disparate service ideologies is a challenging task for policy makers, service providers, and consumers. It is important to understand how these programs began and the context in which these early demonstrations took place.

The disability network has its roots in the advocacy movement and in legislation that promulgated a focus on educational training and rehabilitation. By contrast, services to the elderly, formalized by the Older Americans Act of 1965, had predominantly a group orientation with a focus on socialization, companionship, and a service orientation that counters the frailties of aging by maintaining individuals in the community for as long as possible (Lavin & Doka, 1999; LePore & Janicki, 1990). The disabilities network ideology is person-centered or individualized, as opposed to group-focused, which is the case with older adult services (LePore & Janicki, 1990). This person-centered ideology is exemplified in the New York State Office of Persons with Developmental Disabilities' (OPWDD) mission of "putting people first" that will "result in moving the system towards more high quality person-centered services that focus on outcomes that meet each person's individual needs" (Spitzer & Ritter, 2008, p .2). OPWDD's role is to

provide a continuum of services to persons with intellectual and developmental disabilities, conduct research, and develop programs to respond to the needs of the intellectually and developmentally disabled and coordinate and provide regulatory oversight to a vast network of voluntary community-based service providers (OPWDD, 2009). The New York State Office for the Aging (NYSOFA) is the “lead agency in stimulating, promoting, coordinating, and administering federal, state and local programs and services for older New Yorkers. NYSOFA collaborates with state agencies, county agencies, hundreds of for-profit and nonprofit organizations and academic institutions, and the Area Agencies on Aging throughout New York State, to achieve the mandates of the Older Americans Act” (New York State Plan on Aging, 2007-2011). Each of the fifty-nine counties in New York State administers aging services either through municipalities or through contracts with local providers. In New York City, the local Area Agency on Aging (AAA) is an agency of city government, namely, the New York City Department for the Aging (DFTA). DFTA coordinates and largely funds the vast network of voluntary agencies that provide programs and services to older New Yorkers in the five counties that comprise New York City. DFTA provides administrative oversight to the three core program areas, established through Title III of the Older Americans Act of 1965: senior centers, nutrition programs, and in-home services.

### Demonstration Projects

According to an OPWDD report, authored by LePore & Janicki (1990), early demonstration projects in four counties in New York State were designed to integrate persons with intellectual and developmental disabilities into the general aging

community. Some of the barriers to integrating the general aging and the intellectual and developmental disabilities networks were reported as stemming from attitudinal, communicational, educational, training, fiscal and programmatic challenges. Attitudinal barriers included negative stereotypes about persons with intellectual and developmental disabilities, fear on the part of the intellectually disabled, and the tendency for family members of intellectually disabled older adults to be overprotective and therefore reluctant to allow them to participate in generic aging programs (LePore & Janicki, 1990).

Communication challenges included the lack of information regarding each other's networks of available services as well as barriers that arose due to confidentiality issues. Financial barriers included the fragmentation of funding sources, as well as related challenges resulting from differences in regulatory and reporting standards for these different service networks (LePore & Janicki, 1990).

Programmatic barriers included differences in orientation and programmatic philosophies. For example, the aging service network tended to be more focused on social integration and engagement of participants in leisure activities (LePore & Janicki, 1990). The aging network also typically served a narrower constituency of higher functioning adults at the upper end of the aging spectrum (Lavin & Doka, 1999). Alternatively, the disabilities network served a broader constituency of disabled individuals from birth to death (Lavin & Doka, 1999), with a philosophical focus on the engagement of individuals in active treatment (LePore & Janicki, 1990). Challenges included the lack of adequate supervision and insufficient staffing levels to meet the stricter requirements for persons with intellectual and developmental disabilities. Lack of

transportation and accessibility to program facilities were also noted as barriers to the integration between these two service sectors (LePore & Janicki, 1990).

Hacker et al. (2000) contend that as a cost-containment measure, Area Agencies on Aging may prefer that persons with intellectual and developmental disabilities continue to be served by the disabilities network throughout an individual's life span rather than by the aging network, even when they reach the age that qualifies them to utilize "senior" services. The primary reason for this preference is the availability of richer funding options in the disabilities network in contrast to the older adult network.

A demonstration project funded by the Administration on Aging in 1993 was designed to assess the extent to which AAAs targeted families who were caring for older adults with developmental disabilities as well as the level of organizational preparedness among AAAs to identify and provide services to these families (McCallion & Janicki, 1997). The Administration on Aging administered a survey questionnaire to 635 local directors of AAAs nationwide that measured the extent to which each AAA specifically had:

- allocated funds in their budget to work with these families;
- designated staff to assume the responsibility of working with families of persons with developmental disabilities;
- developed an outreach program to make families aware of service priorities; and
- mentioned serving this population as a priority in their annual plan.

The study found that although a relatively high percentage (75 percent) of AAAs included consideration of the needs of persons with intellectual and developmental disabilities in their annual plans, far fewer (15 percent) actually allocated resources in their budgets. Seventy percent of the AAAs surveyed could not even substantiate how

they estimated the number of families with intellectual and developmental disabilities living within their catchment areas (McCallion & Janicki, 1997).

The increasing concern about the need to increase capacity to meet the needs of older adults with intellectual and developmental disabilities and their caregivers effectively prompted a number of statewide and local groups to form planning councils and coalitions to begin to address the increased needs of this growing population (Stone, 2000). These councils and coalitions developed a variety of integrated models for meeting the needs of this burgeoning subset of the older adult population.

One such integration model was the Texas Project, developed in the mid-1990s by the Texas Planning Council for Developmental Disabilities in collaboration with the Texas Department for the Aging. The Texas Project was developed to integrate services and supports with multiple points of entry so that older Texans with intellectual and developmental disabilities and their families could have culturally relevant and individualized service options. The model utilized the following strategies to achieve these goals (Stone, 2000):

- Coalition building, through establishing cooperative and collaborative relationships at the local level;
- Community outreach activities that included information sessions for key stakeholders to raise awareness of aging issues and disability issues and the available resources;
- Cross training of coalition members, their staffs, family members, and caregivers regarding community resources; and
- Needs assessment to identify gaps in services.

Other models of service integration between the disabilities and the older adult networks, such as pilots launched in Maryland and Virginia (1990–1993), utilized collaboration, outreach, and capacity building across service sectors. These pilot projects highlighted the necessity of cross training as a tenet of successful service system integration and also brought to light the challenges, including availability of funding, sustainability of commitment, continuity of staff, and a shared definition and understanding of the core components of the model (Ansello & Coogle, 2000).

In Florida, another model of service cooperation across the intellectual and developmental disabilities and older adult networks built upon these earlier studies and added informal supports, including caregivers and volunteers, to augment its service model (Sherman & Bloom, 2000). For example, in 1994, integration projects in Florida used senior mentors to accompany and assist individuals with developmental disabilities who attended and participated in senior center activities (Sherman & Bloom, 2000). The mediating role of the senior mentors had a positive impact on overcoming some of the attitudinal barriers described earlier. The participants who were developmentally disabled were also carefully selected to ensure a greater probability of successful integration with the general population of senior center participants. It appears that collaborative models may be effective for persons with the functional capacity to participate in traditional senior activities. However, they are probably less effective for persons with more severe functional limitations.

Demonstration projects awarded to AAAs throughout the country from 1994 to 1996, including those in New York State, mirrored strategies for service integration similar to these earlier projects and achieved consistent results (Hacker, et al., 2000). While

integration across the disabilities and older adult networks represents an attempt to deal with the growing population of older adults with intellectual and developmental disabilities, this model has not been easily realized. Both the older adult and the intellectual and developmental disabilities networks continue to face a number of innate challenges, which seem functions of the existence of separate and discreet funding streams, disparate service philosophies, a lack of coordinated policies, and the silo like structure of government agencies focused on the needs of specific populations (Torres-Gil, 2007).

There are no federal or state policies, programs, or benefits that provide or coordinate services for people aging with disabilities. This does not mean that there is an absence of such policies for older adults and people with disabilities. In fact, there is a rich source of funding and programming for each of those two groups. The problem is that each set of policies is categorical in nature, creating networks of often fragmented and uncoordinated services and programs. This results in program overlap, but more often in gaps in services (Torres-Gil, 2007, p. 252).

Given the inherent challenges of integrating services across the aging and intellectual and developmental disabilities networks, which were reinforced in multiple pilot projects, it can be asserted that energy may be better directed at building capacity within the intellectual and developmental disabilities provider network, as opposed to seeking integration within the older adult network, to provide the accommodations necessary to meet the needs of the ever-increasing demographic of aging adults with intellectual and developmental disabilities. While earlier research (1990s) has helped to document the attempts at coordinating services at the macro level between AAAs and State Disabilities networks that underscore the challenges of bringing disparate service philosophies and funding streams together to serve a common goal (Berkobien & Davis, 2000; Hacker et al., 2000), there is a paucity of research focusing on micro-level efforts implemented at

the service provider level. New York State in particular has vast provider networks serving the needs of both the older adult population and those with intellectual and developmental disabilities. Therefore, an attempt at understanding the organizational and program dynamics involved in addressing the older adult population with intellectual and developmental disabilities is a much more practical application of research and, I would argue, reinforces the need for this particular study.

### Environmental Challenges and Related Studies

Addressing environmental barriers to accommodate the needs of older adults with intellectual and developmental disabilities is a significant factor that has an impact on any service provider's ability to efficaciously meet the needs of this consumer group. As noted earlier, people with intellectual and developmental disabilities often have the need to utilize wheelchairs, walkers, and other assistive devices as they age, yet many of the programs designed to care for their needs cannot accommodate these types of mobility aids. Interestingly, studies that have explored and sought to identify options for overcoming these types of environmental barriers and challenges grew out of the specialty fields focused on dementia within both the disabilities and aging services fields. The recommendations that surfaced from these studies may help to provide valuable insights for identifying ways to address effectively environmental challenges for the broader population of older adults with intellectual and developmental disabilities.

According to Janicki, McCallion, & Dalton (2000), there are three options that voluntary agencies can use to respond to dementia-related changes and challenges that arise when serving persons with intellectual disabilities in community group homes to

make them *dementia capable*<sup>1</sup>. These options include the Aging-in-Place Support model, the In-Place Progression model, and the Referral Out model.

The *Aging-in-Place* support model requires that agencies make changes, readjustments, or interventions in response to changing client needs and as a means of restoring equilibrium in the group home. These changes incorporate increasing levels of staff support and training, adapting the physical environment, and enhancing the care management provided for the identified consumer with dementia.

An agency mission statement or the agency culture should reflect an adherence to a philosophical belief that aging in place is the chosen course. Furthermore, the agency has to back this up with an investment in sound management of the home, close scrutiny of staff capabilities and emotional strength, commitment to additional training and clinical supports, and a fiscal investment in making environmental modifications to the home. It also means agency staff must make a commitment to becoming dementia capable. (Janicki, et al., 2000, p. 396)

The *In-Place Progression model* requires that agencies develop specialized units, and employ staffs who have specialized training in dementia care and, most important, are flexible, and have a commitment to care for people with declining abilities. In this model, the physical environment is already conducive for supporting the long-term care needs of consumers as the disease progresses.

Included in the design are typical homelike features, except that greater emphasis is placed on the therapeutic use of public and private spaces and on designs that provide a secure, safe setting, while encouraging and permitting movement and connectedness to the outside....Implementation of an in-place progression model program requires planning data; the availability of funds to underwrite, develop, and cover operational expenses; and training and education capacities for ensuring a continued source of personnel. (Janicki, et al., 2000, p. 400)

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<sup>1</sup> Dementia capable is defined by Janicki, et al. (2000) as “being able to serve people with dementia, even when services are provided to other people as well” (p. 394).

Lastly, the *Referral Out model* requires that the agency refers the consumers who develop dementia for placement in a nursing home or other specialized long-term care facility. The referral is based upon assessment that their needs cannot successfully be met within their current living environment. There is a significant financial incentive for agencies to opt for this model, since it is quite difficult to secure the funding needed to make adaptations to meet consumers' needs. According to Janicki et al. (2000): "For many agencies, the pressing concern is rising costs associated with care for people with dementia...this is often the result of states' reluctance to revise their daily rates for community care settings once the initial rate is set" ( Janicki et al., 2000, p. 401). The reality of the growing cost of providing care to a medically frail population of older adults with intellectual and developmental disabilities, including those with dementia, provides further justification for the aspect of the study that will explore agencies that value an aging in place scenario or some variation thereof, as opposed to transferring consumers to a nursing home when the care of consumers becomes too costly, both monetarily and in terms of human capital.

A significant study that informed the direction of this proposed study was the "Preparing Community Agencies for Adults Affected by Dementia Project (PCAD)" (Janicki, McCallion, & Dalton, 2002). This study examined how a sample of group home providers responded to and made decisions in relation to one or more adult consumers in their care that had a diagnosis of dementia to facilitate their aging in place.

As part of the PCAD project, survey questionnaires were administered to a modified snowball sampling of agencies in the United States, Canada, Ireland, and the United Kingdom that currently or previously provided services to an adult with a disability or an

adult with dementia. Of the fifty-four group homes that participated in the study, the average age of the adult consumer with reported dementia was 55.1 years, and for those with Down syndrome and dementia the average age was 52.6 years. There were more females (60 percent) than males and two-thirds were Down syndrome. The homes surveyed served an average 6.9 residents and were in operation an average of 12.4 years. A majority of the homes were located in suburban areas, were of one-story design, and had unfenced yards. A majority of the residences had one or more persons diagnosed with or having experienced symptoms of dementia.

Results indicated that providers opted for one of the three placement options mentioned earlier: Aging-in-Place model, In-Place Progression model or Referral Out model. The study revealed that the key factors in outplacement are centered on agency policy around commitment to care, overall composition of resident case mix in the home, behavioral issues of the person with dementia, staff capabilities, safety concerns, funder rules, and regulatory issues. Often the decision to outplace resulted from the negative impact the individual with dementia had on the other residents in the home. However, agencies reported that they experienced little or no outside pressure to retain the individual with dementia (Janicki, Dalton, McCallion, Baxley & Zendell, 2005; Janicki, et al., 2002). The In-Place Progression model occurred most frequently in agencies that already operated several homes and, therefore, had more flexibility in designating one of these homes for a specialized purpose. In these cases, the homes were most likely to be retrofitted to accommodate the needs of the individual with dementia, as opposed to building new structures for this specialized purpose. The study also indicated that at the later stages of dementia progression, individual consumers were more frequently

transferred to long-term care or nursing facilities run either by the same agency or by other agencies. This decision was often the result of disruptive behaviors of the individuals with dementia or increased levels of nursing needs that the agency could not meet within the group home setting. This inability to meet increased nursing needs sometimes arose from the agency's self-assessment. However, regulatory agencies and funding requirements often do not permit the programs/homes to provide a higher level of medical care for persons with diminished functional capacity (Janicki, et.al, 2002).

The researchers stated that the findings of their research analysis indicated that few of the participating group homes reported having made home or environmental modifications to accommodate the needs of their consumers with intellectual disabilities who developed dementia. Additionally, the research findings noted that agencies were slow to initiate increases in staffing and were reluctant to modify the diets of persons with dementia (Janicki, et al., 2005).

In response to the results of the study, PCAD researchers developed a model of planning and service design that supports "dementia capable" programs. The elements of this approach, termed ECEPS, include:

- Early screening and diagnostics involve the collection of baseline performance and medical data to assist in differential diagnosis and periodic reassessments to track disease progression;
- Clinical supports and services involve the use of clinicians trained in dementia diagnosis and interventions such as physicians, psychologists, social workers, nurses;

- **Environmental modifications** include inexpensive home modifications such as change in lighting, painting, landscaping, installing alarms, decluttering, or more extensive structural changes such as retrofitting bathrooms, stairways, widening hallways, and creating barrier free living spaces;
- **Program adaptations** to accommodate the memory issues and declining functioning as disease progresses, adaptations to the programming and structure of an individual's day and with managing their activities; and
- **Specialized care** that involves adapting service structures as disease progresses from a focus of independence in early stages of dementia care to a more structured medical care and supervision in later stages of illness (Janicki, et al., 2000, pp. 190-193).

This research was a broad attempt to survey the issue of organizational decision-making in relationship to the provision of dementia care for persons with intellectual and developmental disabilities. The fact that each country has a unique regulatory environment, which may influence its program design and operations, impedes the ability to make generalized inferences. In addition, the number of individuals with dementia who were studied was relatively low, a factor that may have diluted the responses of individual organizations and group homes. The researchers themselves even reported that most often the agencies were reactive in their response to individuals with dementia, as opposed to being proactive in their efforts to plan ways to meet those consumers' needs.

Community service providers that aspire to support the Aging-in-Place and the In-Place Progression models for older consumers with developmental disabilities, with or

without dementia, must contend with the potential need to make environmental adaptations to their residential and program facilities. There are generally two options when it comes to designing facilities: Agencies can create “built to suit” specialized units with sensitive and flexible designs that safely support persons who presently are or may become more physically debilitated, or there may be existing facilities with more flexible features (Udell, 1999). Environmentally flexible designs and assistive technologies may incorporate the following:

- grab bars, bed rails, and other appliances and cabinetry at wheelchair height;
- raised toilets, hand-held shower faucets, bath chairs, height adjustable sinks;
- roll-in showers and bathtubs, and space for both indoor and outdoor activities;
- single-story structures or elevators in multiple-level facilities;
- sufficient lighting and proper color contrasting; and
- Hoyer lifts, wheelchair-accessible ramps, hallways and doorways

(Day, Carreon & Stump, 2000; Gitlin & Corcoran, 2000; Hutchings, Olsen & Ehrenkrantz, 2000; Udell, 1999).

While integrating these adaptive features in building or renovating facilities is a costly endeavor, it can be much more cost-effective in the long term if it improves overall program accessibility and provides consumers with the ability to remain active and less isolated, reduces their incidences of falls, and helps keep them as independent as possible.

Home modifications can alleviate some of the costs associated with home care, nursing homes, and housing replacement. More important, providing a home that is safe, supportive, and homelike and that includes opportunities for growth and stimulation can enhance an individual’s feeling of competency and independence and self-esteem. (Hutchings et al., 2000, p. 254)

Chaput (2002) reported that small group-home environments provide a better quality of life than specialized care units do for intellectually disabled persons with dementia. Regardless of the setting, it is incumbent upon the direct care and clinical staff to provide the appropriate level of care and to attend to the needs of an aging population of persons with intellectual and developmental disabilities. One would contend that residing in a community home environment is the preferred setting for older adults with intellectual and developmental disabilities, regardless of the origins of the facility and assuming the environment is conducive to safely maintaining individuals as they age. In other words, of the placement options mentioned earlier, Aging-in-Place and the In-Place Progression models are the preferred approaches to the placement options for persons with intellectual and developmental disabilities as they age. This contention is an important premise of the theory of successful aging, which is elucidated in the next section along with the organizational and economic theories that inform the conceptual framework of the proposed study.

The next chapter includes a discussion of the organizational theory of structural inertia, the economic theory of resource dependence, and the gerontological theory of successful aging.

## Chapter IV. Theoretical and Conceptual Framework

This chapter describes the theoretical and conceptual frameworks in which the study was situated. The gerontological theory of successful aging provides the theoretical framework as well as the constructs to which older persons with intellectual and developmental disabilities aspire. Contextual responses from the participating organizations were viewed through the lens of organizational and economic theories.

The economic theory of resource dependency illustrates the interdependent nature of nonprofit organizations on their funding entities. The study illuminates how this dynamic interplay influences the capacity of a nonprofit organization to garner the financial and political resources necessary to serve a growing population of older adults with intellectual and developmental disabilities. The concept of structural inertia, taken from organizational theory, provides a framework for discussions regarding the impact that size, complexity or affiliation of a nonprofit organization has on its ability to initiate the change efforts involved in meeting the demands of an aging constituency with intellectual and developmental disabilities.

### Theory of Successful Aging

Throughout the past few decades, there has been a great deal of discussion about what constitutes successful aging (Baltes & Baltes, 1990; Baltes & Baltes, 1987; Featherman, Smith & Peterson, 1990; Fries, 1990; Schaie, 1990). Early psychological theories of successful aging used a developmental life-course perspective rooted in what is considered “normative” aging (Erickson, Erickson & Kivnick, 1986; Ryff & Heinckle,

1995; Ryff, 1989). One such theory, espoused by the prominent developmental psychologist Erik Erickson, viewed successful aging as being achieved through the attainment of *generativity* and *wisdom* in the later stages of life. Normative theories have been criticized for utilizing a benchmark based on middle- and upper-class white heterosexist normative psychological development and the presumption that society is standardized (Baltes & Baltes, 1990). Psychological theories have also taken into consideration objective criteria for adaptation and development such as cognitive functioning (Schaie, 1990), in addition to considering the *person in environment* (Baltes & Baltes, 1990) as a way of assessing whether one ages successfully. By not setting the criteria for successful aging exclusively on cognitive functioning, the theory broadens its application to include those with intellectual and developmental disabilities and speaks in a broader context to one's adaptive competence regardless of whether those adaptive responses are internal or external to the individual. "Adaptive competence is a generalized capacity to respond with resilience to challenges arising from one's body, mind, and environment" (Featherman, Smith & Paterson, 1990, p. 51).

One such prototypical model or strategy of successful aging involves the principles of *selective optimization with compensation*. Baltes & Baltes (1990) describe this general theory of adaptation as having three interactive components and processes: selection, optimization, and compensation. The process of *selection* refers to a person having fewer options for maximum efficiency domains due to the loss of adaptive functioning as a result of the aging process. The second component involves the principle of *optimization*, which purports that individuals engage in behaviors that support their optimal functioning and maximize their adaptive functioning. Lastly, the element of

*compensation* involves psychological compensation when restrictions exceed a person's ability to adapt by using technology or environmental modifications, such as the use of hearing aids or grab bars (Baltes & Baltes, 1990). These elements will inform this study, as it explores the ways that organizations help to support an older individual's optimal functioning through the adaptation or manipulation of that individual's environment by utilizing adaptive equipment or through alterations to that person's internal (medical, social, psychological) and external environments.

Successful aging from a public health perspective takes into account the benefits of *morbidity compression* (Fries, 1990). This paradigm of successful aging espouses the benefits to individuals and society by delaying the onset or manifestation of disease. The compression of morbidity thesis states: "The species' life span is finite and the onset of chronic disease is relatively easily delayed. Thus, the period from the onset of chronic infirmity to death may be shortened, with benefit, to both individuals and society" (Fries, 1990, p. 35). The study will also explore how organizations support the delayed onset of chronic illness for older consumers through health prevention activities and holistic health and wellness programming, which address the physical, emotional, spiritual, and psychological needs of individuals, and help delay the onset of chronic illness for older consumers with intellectual and developmental disabilities.

Behavioral theories of successful aging have operationalized indicators of successful aging such as coping, life adjustment, and life satisfaction (Brandstadter & Baltes-Gotz, 1990; Rudinger & Thomae, 1990), psychosocial adjustment (Vaillant, 1990), and developmental behavioral genetics (Pederson & Harris, 1990). According to Wendy Lustbader, a well-regarded researcher in gerontology, even persons who are dependent on

others for their care can age successfully by “finding satisfaction and meaning even in a state of dependency, including moments of avid aliveness, true intimacy between family members, and spiritual renewal as indicated by heightened or vivid spiritual experiences and achieving satisfying intimate relationships with family members” (Lustbader, 2000, p. 22). These are all important but less tangible measurements, which therefore will not be used in this study.

A more contemporary application of the theory of successful aging uses multiple criteria by which adults live out their later years with an emphasis on the *positive aspects of aging* (Rowe & Kahn, 1998), and will be used as a conceptual framework for this study. In the landmark MacArthur Foundation Study, an interdisciplinary group of researchers conducted long-term studies in their respective fields that emphasized the positive aspects of aging. Rowe and Kahn (1998) “define successful aging as the ability to maintain three behaviors or characteristics: low risk of disease and disease related disability; high mental and physical function; and active engagement with life” (p. 38). In applying the concepts of successful aging to persons with intellectual and developmental disabilities, Hawkins (1999) names these three central ingredients: health status, perceived life satisfaction, and community membership. According to Hawkins, “aging successfully, or good old age, is characterized by continual acceptance, adaptation, and supports by the social matrix that surrounds the older person, thus maximizing the potential of the three elements” (p. 99).

Janicki (1999) argues for the relevance and utility of applying the theory of successful aging to an intellectually disabled population, especially within the parameters of the third and fourth age of the life-course perspective. In relation to the support strategies

that providers can employ to assist persons with intellectual and developmental disabilities to age successfully, Janicki writes that “supports and services should be designed to help maintain health and physical capacities, provide intellectually and physically stimulating environments, and ensure that social networks and community engagement are utilized to the fullest extent possible” (p. 297). These outcomes, within a conceptual framework of successful aging as it relates to older consumers with intellectual and developmental disabilities, will incorporate:

- encouraging social interaction and community inclusion;
- maintaining the optimal physical and cognitive functioning of the individual;
- preserving the positive personality traits of many consumers with intellectual and developmental disabilities such as their genuine warmth, caring, affable and trusting nature;
- supplying necessary informal and formal supports and services that build on each individual’s strengths as they age; and
- providing safe and stimulating physical environments.

### Resource Dependence Theory

One unit of analysis in this study is the organization and, therefore, it is useful to examine economic theories of organizations to help frame the inherent dynamic interplay between voluntary organizations and government, when the former is dependent on government funding to support service delivery. Organizations are “open systems” that are influenced by environmental factors. As such, survival of an organization depends on its ability to adapt selectively to environmental influences (Huber & Glick, 1995), the

ability to interact with and the capacity to influence those with needed resources (Froelich, 1999; Pfeffer & Salancik, 2003). According to Pfeffer & Salancik (2003), the underlying assumption of resource dependency theory is that “the key to organizational survival is the ability to acquire and maintain resources” (p. 2). Dependence therefore, can be “defined as the product of the importance of a given input or output to the organization and the extent to which it is controlled by relatively few organizations” (p. 50). Similarly, according to Smith (2010), there is value in applying a systems perspective when considering how an organization relates to its external environments, specifically regarding program development: “The program may bring in resources to the organization, which could be the only reason the organization has this program. The program could be strictly public relations because it ‘looks good’ for this organization to have such a program. Or, on the other hand, the program could also be a positive way for an organization to meet the additional needs of the community it serves” (p. 94).

Nonprofit community service providers regularly collaborate with government to provide goods and services financed by government. Salamon (1995) terms this partnership “nonprofit federalism,” as it is the preferred service delivery mechanism that combines the best capabilities of the voluntary sector and of government. The advantages of the nonprofit sector providing human services, as opposed to the government providing these services, include:

- easier access to volunteer resources and the ability to leverage philanthropic funding;
- greater diversity in terms of breadth of services and, therefore, nonprofits provide a more holistic approach to service delivery;

- increased probability that the provider has had experience in a given arena prior to the establishment of a government-funding stream;
- significant flexibility and capacity for program start-up and termination; and
- smaller operations that are closer to the community and, therefore, can provide more personalized service.

Disadvantages of government purchasing services from nonprofit community service providers include:

- inadequate funding to cover the true cost of service delivery;
- increased cost of professionalization;
- lack of a competitive playing field;
- propensity of nonprofit organizations to “follow the funding” and, as a consequence, “mission drift” occurs; and
- loss of autonomy

(Austin, 2003; Gilbert & Terrell, 2002; Guo & Acar, 2005; Salamon, 1995; Young, 2000).

Since government often lacks the capacity to provide services directly, while nonprofit service providers typically have the human but not the financial capital to provide services, their partnerships are often ones based on interdependence (Saidel, 1989). According to Saidel, there are three dimensions of this interdependency: 1) resource-exchange interdependency, 2) political interdependency, and 3) administrative interdependency. The resource-exchange dimension relates to the direction of the exchange, which can be one-way, e.g., from government to provider or from provider to government. It can also be a two-way exchange. Saidel discusses the partnership that

developed between New York State government and community service providers serving the mentally retarded as a result of deinstitutionalization:

Some nonprofit organizations, already offering residential and nonresidential services in local communities, became a necessary ally to state government. Seeking to gain legitimacy in its new roles as advocates of community-based services and a provider of those services, government sought positive relationships with groups already established in the community. The inseparability in this instance of state agency gains in both legitimacy and constituency support illustrates the interconnectedness of the resource and political dimensions. (Saidel, 1989, p. 342)

The political dimension of the interdependency between government and nonprofit service providers involves both the formal and informal roles that the nonprofit providers play in influencing policy decisions and agenda setting and in insulating government from unpopular policy or funding decisions. The administrative dimensions include the exchanges between the state/government and voluntary/nonprofit sectors on issues related to management and organizational efficiency and effectiveness (Saidel, 1989). Therefore, this study will also ask about each organization's relationship with government entities.

The service providers involved in this study are dependent on the regulatory oversight and financial reimbursement for disabilities services from the New York State Office of Persons with Developmental Disabilities (OPWDD). Even though the relationship between OPWDD and nearly seven hundred voluntary service providers throughout New York is one of mutual dependence, the power differential must also be taken into consideration. In New York, there is one predominant funding and regulatory agency in the disabilities services arena. However, there are hundreds of nonprofit service agencies that provide residential and community care to persons with intellectual and developmental disabilities, whose positions of power are diminished by being one of a

vast pool of agencies vying for the same limited number of licenses, funding opportunities, and discretionary resources administered by OPWDD. In light of this reality, resource dependence theory provides the framework for examining the constraints and considerations that agencies contend with as they seek to upgrade their facilities and adapt their programs to serve an increasing population of older disabled adults.

### Structural Inertia Theory

According to Barnett and Carroll (1995), organizational change is defined as “a transformation of an organization between two points in time” ( p. 219). The structural inertia theory of Freeman and Hannan (1984) argues that larger agencies become inert over time and are less likely to change due to their entrenched bureaucratic structure. According to Salamon (1995), as organizations grow in scale and complexity, they become routinized, lack flexibility, and are ineffective to control the tension between “short-term responsiveness and long-term maintenance” (p. 262). As cited in Barnett and Carroll (1995), the empirical evidence regarding the role of organizational size and complexity is mixed. Several studies show that larger organizations have less capacity to change (Delacroix and Swaminathan, as cited in Barnett and Carroll, 1995; Hannan and Freeman, 1984), while others contend that larger organizations inevitably have greater access to resources and, therefore, actually have a greater capacity to change (Aldrich and Auster, 1986; Kimberly, 1976). Other researchers contend that medium sized organizations are most resistant to change (Haveman, 1993). These differing perspectives about organizations’ capacity to implement or resist change point to the need to consider whether the size of an organization influences its ability to adapt and enhance

its services when changes in constituents' needs arise. The study will examine agency characteristics, namely organizational complexity and the agency's affiliation, to ascertain the extent to which these organizational attributes, in addition to the size of an agency, play a role in the service provider's ability to engage in the change efforts necessary to serve their older adult consumers.

## Chapter V. Research Design and Methodology

The following section discusses the importance of the study and the rationale for employing a qualitative multi-case study methodology. Denoted are the units of analysis, scope of the study, sampling strategy, research questions that guided the study, methods employed to collect and analyze data, limitations of study, as well as how risks were mitigated and confidentiality ensured.

### Study Rationale

The documented issues and challenges faced by persons with intellectual and developmental disabilities are much the same as those faced by the general aging population:

- accessible housing (Parish & Lutwick, 2005);
- access to recreation, leisure activities and need for retirement planning (Hodge & Wilhite, 1997; Sutton, Sterns, & Park, 1993; Tedrick, 1997); opportunities for social integration to combat social isolation (Anderson, 1993; Mahon and Mactavish, 2000; Salvatori, Tremblay and Tryssenaar, 2003);
- preventive health, nutrition, and exercise to maintain optimal physical functioning (Frizzell, 1997; Hawkins, 1997; Mughal and Bruckner, 2000);
- reduction in obstacles to end of life care (Botsford, 2004);

- safe and elder-friendly living environments that promote the ability to age in place (Hutchings, Olsen and Ehrenkrantz, 2000; Janicki, McCallion and Dalton, 2002); and
- support for family caregivers (Greenberg, Seltzer, Krauss and Kim, 1997; Haveman, van Berkum, Reijnders and Heller, 1997; Heller and Caldwell, 2006).

While these issues may be the same as those faced by the general aging population, they are often compounded and more challenging for older adults with intellectual disabilities. In light of this burgeoning population, the manner and extent to which the service provider network working with them responds to these challenges as a way to facilitate the successful aging of this growing cohort is the focus of this study.

The study examines how organizations serving older adults with intellectual and developmental disabilities have made strategic decisions related to providing care for their older consumers; the funding implications involved in doing so; and the issues associated with implementing programmatic, environmental, and staffing level changes that help to facilitate or impede an organization's ability to accommodate an aging constituency.

## Research Questions

The primary research questions explored in this study are:

- How have community service agencies adapted their facilities, funding models, medical care and supports, staffing, and programming to accommodate the aging of their consumers with intellectual and developmental disabilities?

- To what extent have the accommodations made by these organizations promoted the successful aging of their older consumers?
- Have the organizational characteristics of affiliation, complexity, and size factored into the service provider's ability to make strategic and adaptive responses to the growing number of older adults in their care?

### Rationale for Qualitative Inquiry and Multiple-Case Study Design

McCracken (1998) writes that qualitative methods have a “complexity capturing ability.” Since the nature of this inquiry is primarily naturalistic and one of exploration, description, and discovery of the phenomenon of interest, the primary qualitative approach is a good fit for this study (Patton, 2002). Further justification for qualitative case study methodology is that the research value rests on its ability to explicate ‘little-known phenomena and innovative systems’ (p. 57). In addition, “a qualitative case study seeks to describe that unit in depth and detail, holistically, and in context” (p. 55).

This qualitative inquiry utilized a multiple-case study methodology to describe, explore, and explain how and why a diverse sample of organizations have made the necessary adaptations to serve a growing population of older adults with intellectual and developmental disabilities. Since this study deals with a “contemporary set of events over which the investigator has little or no control,” a case study methodology has the potential to help unearth a depth of information about the particular issue within a contextual framework (Yin, 2003, p. 9). Further logic for using a multiple-case study design as opposed to a single-case study relates to the potential for future replication and increased externalized generalizability of the findings (Yin, 2003). Yin states that “each case must

be carefully selected so that it either (a) predicts similar results (a literal replication), or (b) predicts contrasting results for predictable reasons (a theoretical replication)” (p. 47). A disadvantage of a multiple-case study design is that “the more cases an individual studies, the greater the lack of depth in any single case” (Creswell, 1998 p. 53).

While a single case may unearth many of the processes adopted by a particular organization, certain idiosyncratic attributes may also prevent the ability to generalize findings to other organizations that serve the same population. Multiple case studies are instrumental in the sense that they provide a means to an end—meaning that the case studies under intense investigation are being carried out in order to explore another or secondary interest (Stake, 1994). My interest was to explore the common experiences of information rich organizations that served a population of older adults with intellectual and developmental disabilities, rather than any single organization. The study is therefore considered applied research, if through the *thick descriptions* that unfolded others make the assumption that the findings also have application in other settings (Geertz, 1973). The study was conducted in some of the major service agencies serving the intellectually disabled population in New York State. However, given the focus, scope, and nature of the selection strategy of the case samples, it is not representative of all organizations in New York that serve older adults with intellectual and developmental disabilities.

### Units of Analysis

Patton (2002) advises the researcher to know what it is she wants to speak to at the end of the study as a rationale for choosing the units of analysis. My aspiration for the study was to unearth the processes by which organizations adapted their facilities and

programming to facilitate the successful aging of their older consumers with intellectual disabilities. Therefore, one unit of analysis for this inquiry was organizations. These organizations shared common and unique experiences related to how they were meeting the needs of an older adult population with intellectual and developmental disabilities. The second unit of analysis was individuals since the study incorporated interviews of twenty-two executives and senior staff members.

### Scope of Study

The scope of the study included specific areas of adaptation including:

- funding models;
- medical and health issues;
- modifications to physical plants;
- specialized programs and services for older adults; and
- workforce issues

The aforementioned themes or adaptation strategies were culled from a review of the pertinent literature and conceptual framework (Marshall & Rossman, 1999) and were merely “sensitizing concepts” to focus data collection and analysis (Patton, 2002, p. 279). While these themes structured the line of inquiry, the case study design provided enough flexibility to work with other important emergent themes as the study progressed (Marshall & Rossman, 1999).

The study also explored the impact of agency complexity on its ability to make the necessary adaptations to serve an increasingly older population. To that end, the study included a varied sample of organizations comprising both single-purpose agencies and

multipurpose voluntary agencies, as differentiated by the scope of programs and types of populations served; faith-based and secular agencies; as well as agencies with varied resources as determined by size of their respective operating budgets.

For example, the study sheds light on the extent to which a single-purpose agency may or may not be more advanced in its change efforts as than a multipurpose agency. One may speculate that since a single-purpose agency has a more focused ability to plan for future needs and has fewer competing priorities to contend with, it will have adapted therefore, its programs and services to a much greater extent to accommodate an aging population of adults with intellectual and developmental disabilities. On the other hand, one may argue that multipurpose agencies have greater resources with which to build capacity to serve the burgeoning population of older adults with intellectual and developmental disabilities, since they typically have diverse funding streams with which to allocate new or enhanced programming. In addition, multiservice agencies may be more adept at integrating services across areas of expertise.

Another organizational characteristic included agency affiliation. For example, a faith-based agency may be more inclined than a secular agency to make the necessary organizational responses because of the moral imperatives its mission compels it to fulfill. Initially, my intent was to explore these assertions in addition to exploring which characteristics (complexity, size, and affiliation) specifically contributed to successful organizational responses to the issues under investigation. To achieve this end, it was necessary to analyze data by individual cases, across themes and across characteristic groupings as shown in Table 9. The reported collective responses across themes are

elucidated in the following chapter on data analysis as well as a discussion of my impressions relative to the aforementioned agency characteristics.

Table 9

*Matrix for Data Collection and Analysis*

Cases	Themes			
	Physical Plant	Fiscal	Health Medical	Program Workforce
Agency 1				
Agency 2				
Agency 3				
Agency 4				
Agency 5				
Agency 6				
Faith-based agencies				
Secular agencies				
Single-purpose agencies				
Multipurpose agencies				
Midsize agencies				
Large-size agencies				

Sampling Strategy

Purposive sampling methods were used to identify organizations. These included maximum variation (in terms of sample complexity) and snowball sampling achieved by enlisting high-level gatekeepers to help gain access to information-rich key informants and/or critical cases. Additionally, critical case sampling fostered the utilization of sites that “yield the most information and have the greatest impact on the development of knowledge” (Patton, 2002, p. 242).

The six organizations that participated in the study were chosen based on their potential to illuminate the issues under investigation. Sampling methodology included

maximum variation to ensure that “selecting a small sample of great diversity will yield two kinds of findings: (1) high quality, detailed descriptions of each case, which are useful for documenting uniquenesses, and (2) important shared patterns that cut across cases and derive their significance from having emerged out of a heterogeneity. Both are important findings in qualitative inquiry” (Patton, 2002 p. 235).

Criteria for inclusion of organizations in the study included, a New York State–based not-for-profit service provider that:

- operated one or more residential programs for the intellectually disabled;
- served adults with intellectual and developmental disabilities ages fifty years and older; and
- provided accessibility to executives and senior-level staff.

A second, purposive sample was comprised of executives and senior-level staff, each of whom had administrative or direct oversight responsibilities for services provided to persons with intellectual and developmental disabilities, inclusive of those ages fifty and older. These executives and senior-level staff were considered “elites”. According to Marshall and Rossman (1999), elites are “individuals...considered to be influential, prominent, and are well-informed people in an organization or community...they are more likely than other participants to be familiar with the legal and financial structure of the organizations” (p. 113). On the other hand, elite participants are difficult to access, and because they are busy people with numerous demands on their time, they may have difficulty finding the time to schedule and keep appointments. Therefore, coordinating interviews may take an inordinate amount of time. Additionally, Marshall and Rossman (1999) contend that elite study participants tend to dominate the conversation and may go

off subject with their own agenda, consequently minimizing the likelihood of gaining significant insight into the topics on which the study is focused.

#### Recruitment of cases and individual participants

A short list of twenty potential organizations that ostensibly met the study criteria was developed through review of the online database of the New York State Association of Community and Residential Agencies (NYSACRA), which listed agencies' geographic service areas as well as the scope of services and populations served. This short list was reviewed in consultation with two senior-level colleagues, both of whom have decades of experience in the disabilities network in New York. This review process sought to ascertain two important conditions: 1) whether or not the organization had the potential to be an information-rich case, and 2) the likelihood of my gaining access, either through my own network connections or by eliciting the assistance of key gatekeepers. This process eliminated two agencies. However, two additional organizations were added to the list of potential study sites. A colleague later recommended these two critical cases based on the knowledge of these agencies having developed aging-specific programming. These twenty potential study sites became the focus of my recruitment efforts.

Upon approval of my study proposal, an application for Dissertation Proposal Clearance for Human Subjects was submitted to the Hunter College Institutional Review Board (IRB) along with a report (Ref# 2401570) that verified that I had passed the requisite Basic Human Research Curriculum of the Collaborative Institutional Training Initiative (CITI), (*Appendix B*). Two extensions were requested and granted from IRB on

June 25, 2011, and June 21, 2012. A CITI refresher course was completed on December 25, 2011 (*Appendix C*).

A letter of introduction, which described the nature of the study along with an invitation to participate, was e-mailed to the executive director or chief operating officer of each potential study site. As a means of improving the rate and duration of response, a template of an approval letter attesting to the willingness to have the organization participate in the study was sent along with the letter of introduction (*Appendices E & F*). The letter provided my telephone numbers and e-mail addresses in the event the agency executive had additional questions or concerns. Two of the executives requested and received more details regarding the scope of the study, time commitments involved, and the agency specific materials and fiscal documents that would be reviewed. Six agencies returned letters of intent, and four others had given verbal approval. Of the ten agencies that expressed interest, three later declined; One cited internal policy conflicts; another stated its unwillingness to share information with a “direct competitor,” even though it had previously signed a letter of intent; and a third agency was unresponsive to myriad attempts at gaining entry.

After conducting twenty-two in-depth interviews with executives and senior-level staff from six agencies and researching to the point of saturation, in consultation with my adviser, I decided not to include another agency in the study.

### Demographics of Study Sample

Six organizations participated in the study. Collectively, the six organizations operated the following programs for persons with intellectual and developmental

disabilities: residential programs, day habilitation, family support, respite services, community habilitation, vocational training, early intervention, primary and specialty health care, clinical services, behavior management, transportation services, early intervention, special education, and summer camps. In addition, collectively the multiservice agencies also provided residential and community support programs for homeless and mentally ill, services for victims of domestic violence, residences and support for veterans, child welfare programs, youth services, early childhood programs, senior centers, and a refugee resettlement program.

The six agencies operated programs and services in the following twenty-three counties in New York State: Kings, Queens, Bronx, New York, Richmond, Orange, Rockland, Columbia, Greene, Dutchess, Putnam, Ulster, Sullivan, Albany, Saratoga, Rensselaer, Warren, Westchester, Fulton, Montgomery, Schenectady, Nassau, and Suffolk. The larger number of counties represented improves the generalizability of the study as far as representing voluntary service organizations in New York State.

Of the study sample, 33% were multipurpose agencies that serve persons with intellectual and developmental disabilities in addition to other populations, and 67% of the study sample consisted of single-purpose agencies that serve only persons with intellectual and developmental disabilities and their families. Midsize agencies with operating budgets greater than \$5 million but less than \$35 million constituted 33% of the sample while 67% were categorized as large-size agencies with operating budgets of more than \$35 million. Five out of six agencies were secular or non-faith-based organizations, and one was faith-based, having been founded by a religious order over one hundred years ago. All six agencies relied heavily on government funding as their

main source of revenue: mean = 98.75% of total budget is from federal, state, and local government (Table 10).

Table 10

*Organizational Characteristics of Case Samples*

<i>(n=6)</i>	Agency	Agency	Agency	Agency	Agency	Agency
	1	2	3	4	5	6
Faith-based			X			
Secular	X	X		X	X	X
Single-purpose		X	X		X	X
Multipurpose	X			X		
Midsize		X	X			
Large-size	X			X	X	X
Public funding (% of total revenue) *	99.66%	99.25%	99.09%	95.15%	99.67%	99.68%

\*Source: Department of Treasury, Form 990: Internal Revenue Service 2009

Three participants in the study were interviewed at Agency 1 and Agency 2. Four participants were interviewed at Agency 3, 4, 5, and 6. The gender composition of participants from Agency 1 and Agency 2 consisted of one male and two females. Participants from Agency 3 consisted of one male and three females. Participants from Agency 4 and Agency 6 consisted of two males and two females. Agency 5 consisted of three male participants and one female. (Table 11)

Table 11

*Number of Informants and Gender Composition per Agency*


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<i>(n=22)</i>	Agency 1	Agency 2	Agency 3	Agency 4	Agency 5	Agency 6
Participants	3	3	4	4	4	4
Male	1	1	1	2	3	2
Female	2	2	3	2	1	2

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Of the 22 individual participants in the study, 45 % were male and 55 % were female. The mean age was 50 years and two months, the median age was 50 years, and the mode was 49 years of age. Race of study sample consisted of 82 % White, 9 % Black, 4.5 % Asian, and 4.5 % Hispanic. (Table 12)

Table 12

## Gender, Age, and Race of Study Participants

<i>(n=22)</i>	Gender	Age	Ethnicity
Male	10 (45%)		
Female	12 (55%)		
30–39 years		1 (5%)	
40–49 years		10 (45%)	
50–59 years		8 (36%)	
60 years or older		3 (14%)	
White			18 (82%)
Black			2 (9%)
Asian			1 (4.5%)
Hispanic			1 (4.5%)

*Note.* Age: mean = 50 years 2 months; median = 50 years; mode = 49 years

Study participants held the following job titles or their equivalent positions within their organization: 9% Chief Financial Officer, 23% Chief Operating Officer, 18% Clinical or Program Director, 18% Division Director, 18% Executive Director, and 14% Medical or Nursing Director. Twenty-three percent were in their current position between one and five years, 27% between 6 and 15 years, 36% between 16 and 25 years, and 3% greater than twenty-five years. (Table 13)

Table 13

## Job Titles of Study Participants and Longevity in Current Position

<i>(n=22)</i>	Position	Years in Position
Chief Financial Officer	2 (9 %)	
Chief Operating Officer	5 (23%)	
Clinical or Program Director	4 (18%)	
Division Director	4 (18%)	
Executive Director	4 (18%)	
Medical or Nursing Director	3 (14%)	
1 –5 years		5 (23%)
6 –15 years		6 (27%)
16–25 years		8 (36%)
➤ 25 years		3 (14%)

## Ethical Considerations

To maintain the anonymity of the organizations under study, pseudonyms were used to identify cases as well as the individual study participants. As mentioned earlier, prior to proposal submission, written consent from the agency chief executive officer attesting to the agency's intention to participate in the study was obtained either verbally or in writing. After the dissertation proposal and IRB approval were garnered, I met with each agency chief executive to discuss the nature of study in detail as well as the expectations regarding their own and their staff's participation. At those meetings, I requested that each executive designate a point person from their agency with whom I could enlist their help with collecting agency documents, identifying potential participants and, if warranted, assisting with coordinating site visits.

Participants were recruited either through written communication or by telephone. To avoid any coercive recruiting tactics, it was important that I reach out to eligible participants rather than have their executive or a designee try to encourage participation in the study. Upon obtaining contact information about eligible participants, I phoned the potential participant to introduce myself, describe the study, and invite them to participate. If the person was amenable, I mailed a letter of introduction to him/her along with consent forms. As requested, all study participants submitted signed consent forms prior to the start of individual interviews. (Appendix F)

The study involved interviewing human subjects and, consequently, had minimal risk. Given the nature of the interview questions and the fact that the agency executives had some knowledge of who on their staff could conceivably participate in the study, issues related to maintaining privacy and confidentiality were addressed throughout the course

of the study. Participants were informed of the risks involved, that their participation was voluntary, and that they could withdraw at any time without penalty and without their respective chief executive knowing whether they withdrew from the study. Participants were also informed that their individual identity and that of their agency would remain confidential in the dissertation manuscript as well as in any reports or publications arising from the study. My contact information and that of my dissertation adviser were distributed to all participants in the event they had any questions or needed further clarification regarding any aspects of the study. Participants were informed of the benefits of participation in the study and were told that they would receive a copy of the report, if requested.

#### Data Collection and Analysis

A variety of data collection methods were used in this study, including semi-structured interviews with key informants in person and by telephone, as well as direct observation and document analysis. The advantage to using converging lines of inquiry is the potential for increasing the construct validity of the study by using multiple sources of evidence to explore the issues under investigation (Yin, 2003). The primary method of data collection was the interview. The advantage of conducting in-depth interviews using a generalized guide is the potential to obtain rich information, to focus the topics of discussion on the concepts of the investigation, and to provide the flexibility to explore information in detail as it unfolds (Patton, 2002). Additionally, telephone interviews can be conveniently scheduled and rescheduled, in addition to saving on travel expenses and time (Smith, 2010).

Data collection included twenty-two recorded in-depth interviews with a sample of “elite” informants comprised of executives and senior staff from six voluntary agencies serving persons with intellectual and developmental disabilities in New York State. Triangulation of data sources and methods enhances the reliability and validity of this study by illuminating both consistencies and inconsistencies in the data (Patton, 2002). “Finding such inconsistencies ought not be viewed as weakening the credibility of results, but rather as offering opportunities for deeper insight into the relationship between inquiry approach and the phenomenon under study” (p. 248). For the agency case samples, interview data was further triangulated through review of strategic plans, demographic data, fiscal reports, annual reports, program brochures, newsletters, documentation to support rate-appeals, training materials, and agency Web sites, as well as through direct observation and my own journal entries. The study includes thematic and descriptive analysis of “within-group similarities coupled with intergroup differences” (Huberman & Miles, 2002, p. 18) of the organizations’ adaptive responses to the issue of serving older consumers.

A study instrument in the form of an interview guide was developed (Appendix G). Originally, the interview guide was comprised of twenty-six open-ended questions in addition to related probing questions. Upon the advice of my committee, the number of interview questions in the guide was distilled to ten generalized questions that collectively addressed the sensitizing concepts mentioned earlier. The interview guide was reviewed for clarity and understanding by a fellow student and, consequently, questions were reworded. The study instrument was piloted on a *friendly agency* and, as such, the instrument was piloted on three of my senior-level co-workers. The pilot

interviews led to my further refining the instrument, thereby ensuring face and content validity.

While accessibility to interview high-level staff was a minor concern prior to recruitment efforts, I had believed that my position as an executive of a large social service agency would afford me opportunities to network with many of these “elite” individuals and would therefore facilitate my gaining access to organizations that met the study criteria. However, my position as chief operating officer of a large human service organization appeared to be more of a liability than an asset as far as my gaining access to agency executives and their staffs. In hindsight, a possible explanation to my having difficulty recruiting organizations stems from a preconceived notion on behalf of agency chief executive officers that, given the opportunity, large organizations acquire smaller organizations either through aggressive procurement practices or by assuming a greater market share, thereby rendering smaller agencies irrelevant. I speculate that, under the guise of student researcher, if granted access, my being privy to sensitive financial data could potentially expose an agency’s operational vulnerabilities and thereby give my employer a competitive advantage. This speculation was validated because, after the chief executive officers signed a letter of intent to participate in the study, three of them never followed through on their initial commitment, despite multiple attempts to gain entry. Of the six agencies that participated in the study, only two agency executives voluntarily provided financial documents, even though this information is public but not readily available. Agencies had submitted these financial documents to OPWDD in prior years to support claims, rate appeals, or price adjustments for services rendered to persons with intellectual and developmental disabilities. I decided not to submit Freedom

of Information Law (FOIL) requests on behalf of the four other agencies because I was trying to maintain their good will and the information was not germane to the study.

Another study limitation included researcher bias and the subjectivity with which interview questions were posed that may have elicited a favorable response. Participant reactivity was also a concern because I worked in the disabilities field and had some knowledge and ideas about the issues under investigation. Study participants may have told me what they believed I wanted to hear or they may have been less than forthcoming in their responses. If so, the veracity of the participant responses would be questionable and would limit insight into the issues under investigation. These limitations were mitigated by:

- peer reviewing interview transcripts;
- de-identifying data for analysis;
- audio taping interviews and transcribing them verbatim; and
- assuming and reinforcing my role as a student-researcher.

In an effort to gain access to three of the six organizations that participated in the study, I enlisted the help of a gatekeeper, a highly regarded executive of a staffing agency with close business relationships with many executive officers of voluntary agencies in the disabilities arena. The gatekeeper brokered three separate meetings of introduction between three chief executive officers of potential organizations and myself. These brief encounters were instrumental in my establishing a rapport and enlisting their trust and subsequent agreement and cooperation with participating in the study.

Individual interviews took place during an eleven-month period (July 2010 through May 2011). During the winter of 2011, five interviews needed to be rescheduled due to

severe snow emergencies. In addition, two executives canceled their scheduled interviews with only a few minutes' notice because of crises that required their immediate attention. As Marshall and Rossman (1999) propose, such is the consequence of working with busy executives who generally have enormous responsibilities and so little time.

I personally conducted all twenty-two interviews, which took place at sites convenient to the participants, most often in their private office or at one of the agency's group homes. Telephone interviews were used to verify and clarify information and to obtain missing demographic data. Each interview lasted between thirty and forty-five minutes and was audio recorded using an Olympus DS-2400 Digital Voice Recorder. Interviews were transcribed verbatim into Microsoft Word© by a professional transcription service, Franklin Square Services Inc., by downloading and uploading audio files into a secure electronic drop-box or by me. Transcription documents were password-protected and transmitted digitally via e-mail attachments and downloaded into my secure home computer. Hard copies of transcripts, as well as digital recordings copied to an encrypted USB stick, were stored in a locked file cabinet in my home office.

Data was managed, organized, and analyzed electronically, with the assistance of the qualitative software NVivo9, a product of QSR International Pty Ltd. I purchased a one-year student license and attended a two-day introductory training on the fundamentals of using the software. Data, inclusive of pertinent documents such as interview transcripts, audio files, notes, financial information, agency specific marketing materials, and annual reports, were downloaded into the software. NVivo9 provided the central repository of agency specific documents.

### Setting the Stage

An important consideration in data analysis is the historical context at the time the study took place. The study was conceptualized and later actualized during the four-year period from September 2008 through September 2012. The collective interviews represent only a snapshot of the subjective reality as expressed within a political and economic climate in New York State and throughout the country. The historical context included the following events:

- The nation was in a severe and protracted economic downturn and experiencing a credit crisis, high unemployment, and slow economic growth.
- National debt spiraled due to stimulus spending, bailout of the banking industry, defense spending related to protracted wars in Afghanistan and Iraq, continuation of the Bush-era tax cuts, and the country's reliance on foreign oil.
- New York State experienced shortfalls in tax revenues due to fewer and smaller bonuses distributed to Wall Street executives, among other factors, resulting in severe funding reductions of state and local government programs.
- New York Budget deficits were 21 billion in 2010, 8.5 billion in 2011 and 10.4 billion in 2012. These revenue shortfalls result in major budget cuts to human service programs.
- The federal and state legislatures became embroiled in partisan politics, thwarting their ability to address the burgeoning financial crisis.
- Medicaid expenditures in New York State accounted for 14 percent of all state spending in 2010.

- President Obama signed into law the Patient Privacy and Affordable Care Act on March 23, 2010. The act expands health coverage and facilitates reforms in health care by setting expectations for chronic disease management, care coordination, and preventive health strategies for persons with special needs.
- After running on a reformist platform, Andrew Cuomo was sworn in as New York State's governor on January 1, 2011.
- Governor Cuomo charged the Medicaid Design Team (MDT) to make recommendations for systemic reforms aimed at stemming growth in spending.
- OPWDD's budget reduction targets were satisfied, in part, by reducing the department's labor force.
- Senior-level staff at OPWDD retired en masse, taking with them the institutional memory.
- Excessive salary compensation and misuse of funding by a select group of voluntary providers resulted in Executive Order 38, establishing salary caps for not for profit executives who do business with New York State as well as setting benchmarks for the voluntary not-for-profit agencies' administrative expenses.
- The Office of Medicaid Inspector General (OMIG) set out to recoup several billion dollars in fraudulent claims and aggressively audited voluntary agencies. By employing controversial extrapolation methods, OMIG imposed unreasonable repayment obligations on several voluntary agencies.
- The federal and state legislatures were paralyzed by partisan politics that crippled decisive and bold actions needed to ameliorate the burgeoning budget crisis.

- OPWDD was under intense scrutiny resulting from the scandalous series of *New York Times* articles entitled “Abused and Used,” which focused, in part, on the abusive and neglectful treatment of consumers by state workers, labor and union issues, the inconsistent reporting of incidents of abuse, the lack of accountability of state workers, funding abuses, and other negative coverage. These articles put OPWDD in the spotlight, which prompted knee-jerk reactions of expanded regulations and unfunded mandates that were imposed on the voluntary sector.
- The Eastern seaboard suffered the ravages of Super-storm Sandy. Estimates of funding required to rebuild affected communities, restore utilities, and improve the infrastructure of New York’s waterways, shoreline, and electric grids are estimated to be upwards of \$50 billion. Governor Cuomo along with federal and local officials appealed to Congress for disaster relief while the country sat at the edge of the fiscal cliff.

The events listed above set the context in which these interviews took place and the data was analyzed and reported. The economic crisis, New York State Medicaid reform initiatives, and the Affordable Care Act provide the “perfect climate for purposeful reinvention”, as stated by one of the participating agency’s executive director.

OPWDD’s “People First Waiver”, if approved, provides the scaffolding to address many of the challenges and bureaucratic barriers that service organizations face as they try to serve the ever-growing population of older persons with intellectual and developmental disabilities.

The following chapter reports the findings of the study and my interpretations of those findings including, when applicable, a discussion of how organizational characteristics

(agency size, complexity, and affiliation) impacted the degree to which participating agencies had proactively or reactively responded to the challenges of serving the growing population of older persons with intellectual and developmental disabilities.

## Chapter VI. Findings of Study

The purpose of the study is to explore the adaptations community service providers have made to accommodate a growing population of persons with intellectual and developmental disabilities that are aging. This section discusses findings derived from twenty-two semi-structured interviews with executives and senior-level staff from six provider agencies domiciled in New York State. These interviews took place over an eleven-month period, from June 2010 to May 2011. The study was bounded by time as well as by a focus on pre-established themes. Time constraints were imposed in an effort to focus the areas of exploration and make the process manageable within the allotted time to complete the doctoral dissertation.

The study findings are structured in a form that Yin (2002) refers to as “linear-analytic” and that incorporates a cross-case synthesis, and in which “an exploratory case may cover the issue or problem being explored, the methods of exploration, and the conclusions (for further research). In this (linear-analytic) study, no separate chapters or sections are devoted to individual cases. Rather, your entire report may consist of the cross-case analysis, whether purely descriptive or also covering explanatory topics” (p. 149). The decision to format data analysis and findings using this approach was also made in consideration for maintaining the anonymity of the individual participants as well as that of the participating agencies. A cross-case analysis of findings is discussed as it relates to specified themes (physical plant, medical and health, finance, programming) and by the specific attributes (complexity, size, affiliation) of the participating agencies. This analysis will examine the extent to which these attributes

had played a role, if any, in the agencies' adaptive responses to the growing number of older adults in their care.

## Physical Plant

### *Housing Stock.*

The six organizations operate community based group homes that house persons with intellectual and developmental disabilities, some of whom are older adults. A complex variety of physical structures, some of which are leased from parishes or private property owners or are owned by the provider agency, house the consumers of the voluntary service providers. In the words of the study participants, these structures included condominiums, coops, apartments, single-family homes, multifamily dwellings, fully detached homes, apartments in multistory buildings, semidetached homes, farm houses, vertical homes, single-level homes, multilevel homes, Levitt-style homes, brownstones, Colonial style homes, Victorian homes, parish properties, former rectories and convents, single family homes *on steroids* (numerous expansions or additions), or former government buildings. Five of six organizations owned their ICFs and IRAs, and five of six participating agencies both own and lease their IRAs from commercial property owners.<sup>1</sup> One of the six agencies leased its properties exclusively from commercial property owners or from the Roman Catholic diocese.

The physical plant structures where the six provider agencies house consumers consist of many different types of community based group homes that were built anywhere from

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<sup>1</sup> Under auspices of NYS Department of Health, property is considered a restricted asset as a facility must be used for the stated purpose, and if the sponsoring agency divests interest in operating the program, ownership of property could revert back to the state or be assigned to a different sponsoring agency.

the beginning of the twentieth century to more recent years, with some structures being more conducive than others for allowing consumers to age in place.

Irrespective of the type and design of community-based group homes, the physical structures are indistinguishable from other homes on the same block or in the same neighborhood, meaning that there is little visible indication that the residences house people with intellectual and developmental disabilities.

One of the things you will hear in this county is that we blend in so well. Aside from, perhaps, the number of cars that are parked out in front of the home, we are good neighbors. We upkeep the home on par, if not better, than the rest of the community. Our houses are usually the nicest ones. They do not look any different.. You would not drive up to one of our homes and say that is a group home. We fit into the community.. We do nothing to change the character of the community.

Our homes that have ramps had them put in the back of the homes, again to just fit into the community and not cause any type of mischaracterization, eyesore or disturbance to the people around the house. We look for houses that look like a house that you and I live in.

Establishing group homes in the community is often met with great resistance since property owners fear their property values are diminished when a group home or a cluster of group homes populate a geographic area. If a sponsoring agency plans to establish a group home in an area zoned for single-family residences, it must notify the community board or the relative municipality for a public hearing and determination of a saturation study, to see if the proposed location is located in an area dense with other community residences (Schonfeld, 1984). The municipality may approve or recommend an alternative location. However, the state has some overriding authority established by the Padavan Law, which was enacted in New York State in 1978 and “which attempted to facilitate the development of community residences which give municipalities some input

into the selection of residence locations” (Schonfeld, 1984, p. 283).<sup>1</sup> Although a sponsoring agency could muster the political will to override a negative decision, the preference is to locate group homes in communities that are welcoming to persons with intellectual and developmental disabilities or, at best, are not hostile to them. In order to minimize any negative backlash from the community, it is important that the physical structures are indistinguishable to other homes and blend into the community at large.

The six agencies participating in the study house persons with intellectual and developmental disabilities in various residential structures. Some of these residences are more conducive than others to alterations necessary to accommodate an older adult population. Others have physical plants that make alterations difficult, if not impossible, and therefore are less conducive to affording consumers the opportunity to age in place. The consensus among informants was that retrofitting existing facilities is often more costly and complicated than building a barrier-free and environmentally- friendly facility from the ground up. The latter being their preference so that consumers can *age in place*. However, this is not always possible given the high cost of construction, as well as the human and monetary transaction costs expended to retrofit existing facilities.

#### *Stairs from Here to Heaven.*

The need for barrier-free residences seems to be one of the salient issues as it relates to an agency’s capacity to continue to serve an older adult population. Many consumers, as they age, lose their ability to ambulate or have greater difficulty ambulating without assistance. Dwellings with several levels of steps create the largest impediment to maintaining a person with mobility issues safely at home. Those consumers with

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<sup>1</sup> 1978 N.Y. Laws ch.468, §2

ambulation issues have difficulty negotiating steps and with moving around freely with or without assistance, whether on their own, in wheelchairs, or with walkers. In multilevel dwellings, having bedrooms on the second floor creates an unsafe situation.

An individual who was in, when they first moved into a group home, if this is the same home that they've been in for many, many years, and if they had an upstairs bedroom, and if they're having ambulation problems and there isn't a chairlift or there isn't something to help them be independent and accessing the stairs or what have you— that has to be looked at.

We have stairs in the front, stairs within the programs. That what I was saying earlier why it's going to be difficult for folks to be aging in place, even folks who are on the younger side of the spectrum, because I don't have one building, one house that I think doesn't have any stairs in front and that you walk straight in.

Usually we plan facilities with accessibility in mind. There are times, if it's a two-story residence, that we may have to switch bedrooms as someone either ages or even has a nonfunctioning leg and there's some necessity for them not to utilize the stairs.

Well, it's a difficult time with someone, say, live in a brownstone, a three-floor walkup which they've been living there for twenty-five years to try to get them placement from one place to another. If they need a wheelchair-accessible facility, it is extremely difficult, extremely challenging because of the red tape and the politics that are involved in getting approvals.

A person with an intellectual or developmental disability may have functioned well for twenty or thirty years residing in the same one-family, multilevel brownstone-type building. As that person ages in place and becomes increasingly frail, the person may no longer be able to negotiate the long stairways and narrow corridors that are typical in these structures. Brownstone buildings, common to urban areas such as Park Slope, Crown Heights, and Brooklyn Heights, are generally narrow structures attached on both sides. The buildings are often landmarked, making any alteration more expensive.

Architecturally, there is inadequate interior space to install an elevator within the facility or to build a shaft on an exterior wall and install an elevator on the outside of the building. Chairlifts or stair glides are not necessarily good options for occupants of Brownstone-type structures since often the stairways are too narrow to accommodate the resident who, while secured in a chairlift, must have another person escort him or her as they ascend and descend the stairs.<sup>1</sup>

The majority of our houses are brownstone walk-ups, so we are not talking just one flight. We're talking a steep, steep concrete stairway to get up to the front door and then we're talking another two flights up to get to the bedrooms.... We don't have any ranch-style, like Long Islanders. I have been to some of these group homes, beautiful, ranch-style, free-flowing, airy—not in the city. It is difficult.

We have difficulty in buildings, which are one-family homes. I mean, there are some that are two-family homes, no elevator access. We have stairs in front, and folks have to go up the stairs and then straight in. Some of them have Brownstones where the stairs are from here to heaven. So it is impractical that for them to, even if they could, walk into the bottom floor, but there's nothing there other than a kitchen. It's not a living space, so that doesn't really help them much.

The executive director of a medium-size, single-purpose agency plans for environmental modifications proactively as opposed to event-based, reactive modifications. Even though the proposed environmental modification is person-specific, the executive director, who also functions as the nursing director, anticipates the future needs of her older residents and, in doing so, proactively finds the funds to make the necessary modifications to the group home so that the resident(s) may age in place.

We have also been utilizing some person-specific grants for some alterations through OPWDD so that we can alter, if we need to, something person-specific. I try to anticipate what our people need and then apply to OPWDD for funding to make the necessary repairs before an actual crisis.

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<sup>1</sup> Center, J, expert in housing development, personal conversation.

In contrast, large-size, multipurpose agencies are more likely to energize reactively to a crisis. For example, a resident may experience a fall before the agency plans an environmental modification, which may have prevented the resident from falling in the first place. In instances where requests for funding are denied by OPWDD, the decision is more likely to be accepted as opposed to expending energy advocating for necessary funding to make modifications that would facilitate the aging in place of its residents.

We have a house we're about to renovate in Queens where we have people in wheelchairs who really have been limited to one floor. And this is mostly aging issues, but accidents, you fall, you fracture a hip, I mean, it's related to aging but not exclusive. And these folks are limited to one floor in the house, so now at least we're renovating the entire house. We're going to have an elevator, so they can go to more than one floor. Rather than just the dining room and the kitchen, they can go to a living room, they can go to a recreation room, and they can have a bedroom on the second floor. It's an ongoing issue with an ongoing impact for us.

#### *Shared Bedrooms.*

A significant physical limitation of the current housing stock is the limited space and need for consumers to share bedrooms. This limitation presents issues with privacy that exacerbate as a person ages and their medical and physical needs increase and become more complex. Smaller bedrooms that are shared with another intellectually disabled person do not easily accommodate equipment such as wheelchairs, lifts, and walkers. Alternatively, spacious private bedrooms are preferable for reasons such as the disparate tolerance levels of residents relating to cleanliness and organization. For example:

People with autism who have an obsessive compulsive disorder where if they put something in a certain place. I think these were serious barriers when these people were sharing rooms.

As our individuals get older, they become more protective of their space and they become more irritable when people get in their way. We do have single bedrooms now and that has helped a lot.

We have overcome that [conflicts] by providing single rooms for all our individuals, so that helps a lot.

Residents with dementia often experience “sun downing,” whereby they confuse days with nights. These residents may be easily agitated, have frequent behavioral outbursts, experience severe anxiety, or fail to recognize their caretakers or their housemates. Older persons with intellectual and developmental disabilities as well as co-occurring dementia may lose their ability to distinguish the functional purpose of everyday household items such as utensils, furniture, and a toilet bowl. A nursing director describes the necessity of private bedrooms for older consumers with dementia with this example:

If, for example, I know how to use a bathroom on a regular basis and then all of a sudden I don't know that I need to go to the bathroom to move my bowels. So, here, staff has to really look at times and really monitor toileting habits of the person. This will just make sure that the times the person moves their bowels so the staff are catching it before it has happened so they can accompany the person to the bathroom in anticipation of a BM [bowel movement]. They have to start very quickly, to put the person on the toilet by five in the morning or it's going to be all over the bedroom. For example, instead of sitting on a chair, the person was just trying to sit on a table or thinking that the chair is the toilet.

For older persons with intellectual and developmental disabilities and dementia, negotiating the residence becomes exceedingly difficult, if not dangerous, without one-to-one supervision, even if the older person is not mobility-impaired. Additional staffing and supervision are required to manage difficult behaviors that often manifest in persons with dementia-related illnesses.

It means you are going to have to do much more than just put somebody on the toilet. You are going to have to shower the consumer again, you

have to clean the area around, and there is another person in the room who could start having an outburst because, oh, it smells bad, and “Do you know I want to sleep?”

In addition, the behaviors that some older person with dementia exhibits may impose hardships on their housemates who share the home’s congregate living space and even more so for the person who shares a bedroom with that older person.

Most of our consumers share a bedroom with another individual. And when you have dementia or Alzheimer's start really getting to the person every day, regular leaving the routine, it's not only affects the person, but it affects the person who is with him sharing the bedroom.

The last four homes that we have opened have some privates. So, not having to deal with roommate issues is a real godsend.

We opened four homes. It was nice because we changed those to being all individual rooms, which is just wonderful.

### *Fire Safety.*

A major concern for participants was the ability of residential staff to evacuate consumers safely in the event of a fire. In all state-funded residences for persons with disabilities there are strict regulations regarding fire safety. Persons with disabilities often have physical limitations that affect their ability to evacuate under their own power or lack self-preservation skills such as an ability to follow instructions in the event of a fire. OPWDD regulations<sup>1</sup> require frequent and documented unannounced fire safety drills that take place during regular hours and at night when consumers are asleep. These drills are quite disruptive therefore staff may not be conducting fire drills exactly as

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<sup>1</sup> Regulations are available in Health Care Occupancy Chapter of the 2000 Life Safety Code:  
[http://www.archives.gov/federal\\_register/code\\_of\\_federal\\_regulation/ibr/\\_locations.html](http://www.archives.gov/federal_register/code_of_federal_regulation/ibr/_locations.html)

required by regulation. Consequently, the drills rarely simulate an actual emergency, and therefore staff and consumers may be ill prepared to evacuate in the event of an actual fire. In addition, the types of materials used in construction are of concern, as are the fire safety systems such as sprinklers and combustible materials. Respondents raised the following fire safety concerns:

You need to worry about water pressure to make sure that there is enough pressure to bring water up from the well to your existing location. Because you are dealing with the aged or medically frail, you're going to probably have a sprinkler system sometimes or a shelter in-kind. You're going to go for a different life safety code. The Wells situation in upstate New York where they had a fire, the state opted for the same model [building code] as residential, but their pumps for sprinkler weren't strong enough.

Our sprinkler system is involved and that has really helped. It has different doors that will close automatically in case there is a fire in the facility. Some facilities where we have blind consumers, we have bed shakers. If it is a deaf or blind consumer, the bed will shake when a fire is in. A person is trained that when a bed is shaking, it means to get up and leave.

On March 21, 2009, a fire at Riverview Residence, a state-operated IRA in Wells, New York, that housed nine persons with intellectual and developmental disabilities who lacked self-preservation skills, resulted in the death of four of its residents. The State of New York County Court Grand Jury Investigation (2009) brought to light the challenges of safely evacuating persons with intellectual and developmental disabilities who lack self-preservation skills. The investigation reinforced the importance of following the highest standards for fire safety in residences that house highly vulnerable populations. The Riverview IRA was built in 2008, only one year before the fire took place. Although the facility had many fire safety features consistent with a one-family residence as

required by law, it lacked the more robust features required in multifamily buildings and institutions. As stated in the aforementioned grand jury investigation:

These included a fire alarm system, a fire sprinkler system, emergency lighting and exit signage, fire extinguishers as well as numerous construction features....These features were still not commensurate with the requirements of the New York State Fire Protection and building code for an I2 [institutional] occupancy, which were circumvented by determining the homes to be residential [a loophole, albeit a detrimental one] for the purposes of building codes as well as zoning (p. 1).

The grand jury investigators concluded that had the sprinkler system been extended to the attic space and had the roof been made of fire retardant materials, the fire would have spread more slowly and would most likely have resulted in the safe evacuation of staff and all of the residents. One of several recommendations of the grand jury investigation was having a uniform building code that includes fire and safety features that protect the health and safety of individuals. The report states: “Here does not exist for all areas of the state a single, adequate, enforceable code establishing minimum standards for fire protection and construction, maintenance and use of materials in buildings” (p. 17). The tragic fire in upstate New York has raised the consciousness of the critical importance of fire safety, staff training, and compliance with fire drills and documentation. The safe evacuation of consumers who are aging and experiencing mobility issues or those with a co-occurring disorder such as dementia or have a respiratory disease requiring oxygen may need one-to-one staff or two-to-one staff to assist with evacuation in the event of a fire. This is a costly but necessary measure to ensure that in the event of a fire, older consumers can be evacuated safely or moved to a contained area that is accessible by firefighters for easier rescue.

*Overcoming Physical Barriers.*

Each of the six agencies participating in the study has made some type of accommodation to one or more of their group homes due to the changing needs of its older consumers. Some agencies have been proactive in their attempts at developing barrier-free housing and others have done so more reactively when, for example, one of their consumers experienced a fall and consequently fractured a hip. Other examples include reactionary responses to a consumer who suffered a stroke, or developed dementia, or had a chronic or progressive illness and could no longer safely navigate areas of the home. According to participants, accommodations incorporated many of the following features as part of minor alterations or repairs that are more extensive:

- moving a person's bedroom to the first floor of a multilevel residence;
- downsizing a home to allow more of the remaining residents to have private bedrooms instead of shared bedrooms;
- installing ramps, elevators, grab bars, kick guards, walk-in tubs and showers, chairlift or stair guides;
- widening doorways and corridors, lowering counters and sinks, installing tracking for privacy curtains;
- installing adaptive equipment and assistive technology such as Hoyer lifts, walk-in tubs, monitors and alarms and hospital beds;
- upgrading the fire safety systems;
- building homelike nursing and staff work areas designed to facilitate consumer observation;

- improving lighting and decorating residences using elder-friendly fabrics, furniture, and contrasting color schemes; and
- developing and building new single-level residences that have large bathrooms, wide corridors, private bedrooms, and ample congregate space.

Study participants stressed the importance and value of gathering input from staff as well as from older consumers when planning a renovation. Direct care and clinical staff are the ones most familiar with the day-to-day struggles and needs of each consumer, and they are sensitive to their personal limitations as well as the physical challenges that impede the ability of the older residents to age in place comfortably and safely. Input from staff as well as from consumers was valued by two participant agencies as they developed new age-friendly housing or when they renovated existing structures.

We had an occupational therapist on staff until recently who had worked for OMRDD for twenty or twenty-five years before he joined us. We used him as the in-house expert in terms of physical plant design.... He would sit with the architect. He would sit with the program managers. He would sit with the clinical team and just identify by asking: What are the clinical needs? What are the things that we've seen in other locations that are problematic? His input was very valuable.

The input from consumers on design of facility is also very important since they must navigate the facility day in and day out. At least from this perspective— this is what is difficult for me as opposed to how to solve the issue. If an architect or designer knows exactly what those physical challenges are, then they will be better able to problem-solve design issues to accommodate the physical needs of the residents.

We asked people who are going to live there, what do they want to see? We had them work with the architects, and they changed things around a little bit. Things that the architect and staff had not thought of. All the doors are now on an angle because it is easier for a wheelchair to go in. Bathrooms are situated a little differently. In the past, we would ask them about their color and preferences in décor and that kind of stuff, but never in terms of accessibility and what would work for them.

*Upstate vs. Downstate.*

An important difference among participating agencies was their ability to develop barrier-free residences either reactively or proactively. Several executives of agencies from downstate New York had been unsuccessful with attempts to develop group homes from the ground up. These executives claimed that they had difficulty locating reasonably priced property that had a large enough footprint to build single-level, barrier-free structures. Comparatively, participants from upstate New York report an easier time locating property that is reasonably priced with a footprint generous enough to build homes that are barrier-free.

Upstate, they have property. They have lawns. They can construct nice porches for people to go and sit on. It is cheaper to do that, but that goes against the grain of what OPWDD wants to do with respect to allowing people to age in their home communities. It is going to be a horrific problem.

Well, upstate where I come from I would say 80 percent is new construction, so you worked with an architect to design exactly what you need, for \$500,000, \$600,000, you can construct a nice ten or twelve-person residence.

All of our homes are in suburban areas. One of our three ICFs was a ranch that was expanded. We have two other ICFs where we had additions put on. Two of them have an upstairs, a first floor, second floor, and a basement. Our IRAs are both two-story buildings, single-family homes. The ones that we opened for our aging and medically frail were ranch-style homes.

It's a known fact that back in the 1980s, when agencies weren't able to modify existing physical plants for the more involved ICF consumers or even the more behaviorally challenged individuals, they [OPWDD] looked at agencies upstate where there was open land, they could do ground-up construction, you could address accessibility issues, and knock it off right from the get-go.

We actually have about 77 percent barrier-free beds now. It's a great resource that many of our homes are barrier free, and we can because we are upstate. So, it is certainly different than in the city.

Findings from the interviews indicated there was a consensus among participants agencies located downstate, inclusive of single-purpose, multipurpose, large-size, faith-based, and secular agencies, was that building or developing group homes within the confines of New York City was a challenge due primarily to the dearth of land and the skyrocketing costs of real estate. For downstate urban residents, the struggles in building residences made implementing the policy of aging in place even more difficult. The experience of service providers in upstate rural areas was much different than their downstate counterparts. The availability of land, which could be acquired less expensively, afforded the providers opportunity to build more barrier free group homes so that residents could more readily age in place.

At one point, I looked for vacant land for another project. I found a piece of property over in Queens right off the Belt Parkway. We're not talking great residential areas; like commercial warehouse space off the airport, and stuff, but there was vacant land, and they wanted \$15 million for this piece of vacant land that I think the MTA was going to buy and put up a warehouse. You cannot compete with that. There is recognition that commercial space in New York City is extremely valuable and real estate in general is very valuable, but upstate land is cheap.

In terms of physical barriers [in New York City], you have two things going on. One is you have a problem with site selection and whether you have an overpopulation [of group homes in close proximity]. Two, you have challenges with just the physical plants. Right now, I am looking to open two facilities in the city and, optimally, it would be nice if they were barrier-free, but it would have been nicer if they were on a single floor instead of two or three floors.

I have residences that are three floors high. Regardless of whether a person has an ambulation problem, at sixty-five, climbing up three flights of stairs is a problem. These are not places that you could put that nice

little elevated chair that goes up. It is just far too narrow. There are some advantages to having property that you can build on, but you also can't move the thirty thousand people who are currently being served in the city upstate.

I do know agencies that were able to retrofit their homes in order to accommodate older residents. However, this was quite costly for OPWDD, as well as for the agency. And it does not always work within the constraints of the [urban] areas that we are in. Often, there is very little space to spread, to put additions to the house. If you encroach on the neighbor's property or in the back yard [a common occurrence in urban areas], then they are going to tell you, "Well, what about the other folks living in the house? And why should they have a little back yard?" As soon as they say one thing out of one side of their mouth about having them age in place, but out the other side. I think the way they operate is they really have you looking elsewhere in other agencies for potential spots.

According to one participant, the state would grant money to agencies for renovations however there was no overall plan.

As I mentioned before, there are a couple facilities where we have gotten money from OPWDD to renovate them. We are also talking about building new facilities so that they can accommodate these folks, but there is no grand scheme.

### *Pathways to Placement.*

A pattern emerged when study participants discussed how their staff goes about finding alternative residential placements when their consumers require a more accessible living situation. (Figure 3)

The first priority of the agency is to have individuals continue to reside in their own home (age in place) despite their physical limitations. To that end, the agency will move the consumer to a bedroom on the first floor where there is easy access to a bathroom, dining area, and living space. In multilevel structures, this option is exhausted rather

quickly due to the limited number of bedrooms that a facility can realistically accommodate without compromising the comfort and needs of other housemates.

Facilities usually have a very large dining room and a sitting room attached to the dining room or to the living room. We have a breakfast room and a kitchen usually on the first floor. In a few of our houses, we have turned the sitting room into a bedroom in order to accommodate the individual who is there. We have also turned many of our bathrooms, which were not accessible bathrooms, into non-ambulatory bathrooms by widening them and extending them into an adjacent room.

If an accommodation cannot be made in the person's own group home, then the agency will look within its own portfolio of group homes. If a vacancy exists in a barrier-free residence that the agency operates, the person is transferred to that group home. If no opportunity for placement were available within the agency, the next step would be to find a placement within the informal network of agencies, albeit within the same borough or county where the consumer currently resides.

I know many of the apartments and group homes are switching individuals from one place to another with their consent so that they are comfortable. I know many agencies are doing that because it's just something that needs to be done.

Whenever possible, we try to support them where they live. It does not always work out. Barrier-free is the biggest issue that can come up, where they really need accessibility. And, if they still happen to be in a home that isn't barrier-free, they may have to move to another home within our agency.

Individuals who display a problem with ambulating and their bedrooms are on various floors, so that becomes a problem unless you can put a chairlift at the place. We may need to look at relocating them. We certainly network enough that we know of other agencies that have nonam[bulatory] settings, but we want to try to help individuals to age in place.

If no placement can be found through the informal network, the agency will reach out to OPWDD to see if they can identify a suitable placement from within the broader provider network or in one of the rare homes designed for medically frail persons with intellectual and developmental disabilities. If this step proves fruitless, the person will be placed in a nursing home as the option of last resort. Placement in a nursing home is perceived by participants as the least desirable option since it poses the greatest disruption in the person's continuity of care. As mentioned earlier, change is difficult for persons with intellectual and developmental disabilities. Therefore, any move will take a period of adjustment. Nursing home staff may also be ill equipped or unfamiliar with the unique long-term care needs of persons with intellectual and developmental disabilities.

At some point, when hospitalization increases due to infection, due to all kinds of other issues that require nursing care, then you really have to say we will seek twenty-four-hour nursing in our own rehabilitative system. Many agencies have facilities that are like mini nursing homes, which have a twenty-four-hour nurse on-site. We do not like nursing homes, but sometimes when we have no choice, we have no choice.

Then we have a moral obligation to the people we serve...I don't want them to ship them off to a nursing home because in nursing homes they are going to be forgotten about, because they're not going to recognize the fact that they have an intellectual disability. If I had some type of setting that we have a skilled nursing home or some type of palliative care center for aging people, I think it would be much better. I think the concept [was] lost on OPWDD.

If the person is rehabilitated and no longer needs to be in a nursing home, the process commences in reverse. Often times, nursing home stays are prolonged due to the limited number of discharge options and this causes undue hardship for the consumer and for the agency that holds that consumer's bed vacant in the unlikely event the person can return to the group home.

We don't send our consumers—don't get us wrong—to any nursing homes that is in New York because we really try, we pick the best of the best from our understanding of who is familiar with this population and who

we really have a good relationship with...and we will meet several times during that stay, and they will let us know if this is a limitation right here. Then we might have to meet again and decide if we are going to be able to accommodate the specific needs for the individual, or we will have to look for alternative placement. It's not always that we can bring the person back.

Agencies that either reactively or proactively initiate construction to an existing group home face challenges procuring capital funding, but also with finding alternative living arrangements for those consumers currently living in the group home during construction. These temporary living arrangements are often prolonged if construction is delayed for any reason, which is not an uncommon phenomenon for New York.

We have a house we're about to renovate in Queens....For this renovation, there's an extended stay hotel out by the airport and they have handicapped-accessible bathrooms on the first floor, so it's like an eat-in kitchen with chairs. I believe two of the bedrooms have handicapped-accessible bathrooms. So we will take over eight rooms for this renovation, including office space.

Emotionally, it is disruptive on the consumers. I mean, I am anticipating there are one or two consumers who are going to have a rough time, simply because they're set in their ways; they don't like change.

The most successful and least disruptive projects are done by agencies that have respite beds available to use as swing space where they can relocate consumers while their home is being renovated. Respite beds are for consumers who require rehabilitation on a short-term basis, such as a post-hospital discharge following knee surgery.

A respite home is a certified home that does not have permanent residents. So you can come to our respite for one of many reasons as a temporary stay. Generally, we get approval from OPWDD if the individual already lives in a certified setting.

One chief operating officer of a large-size, single-purpose, and secular agency had the foresight to develop, proactively, respite beds for any one of the 350 residents in their care that most likely will have an event-based need for short-term placement. Respite

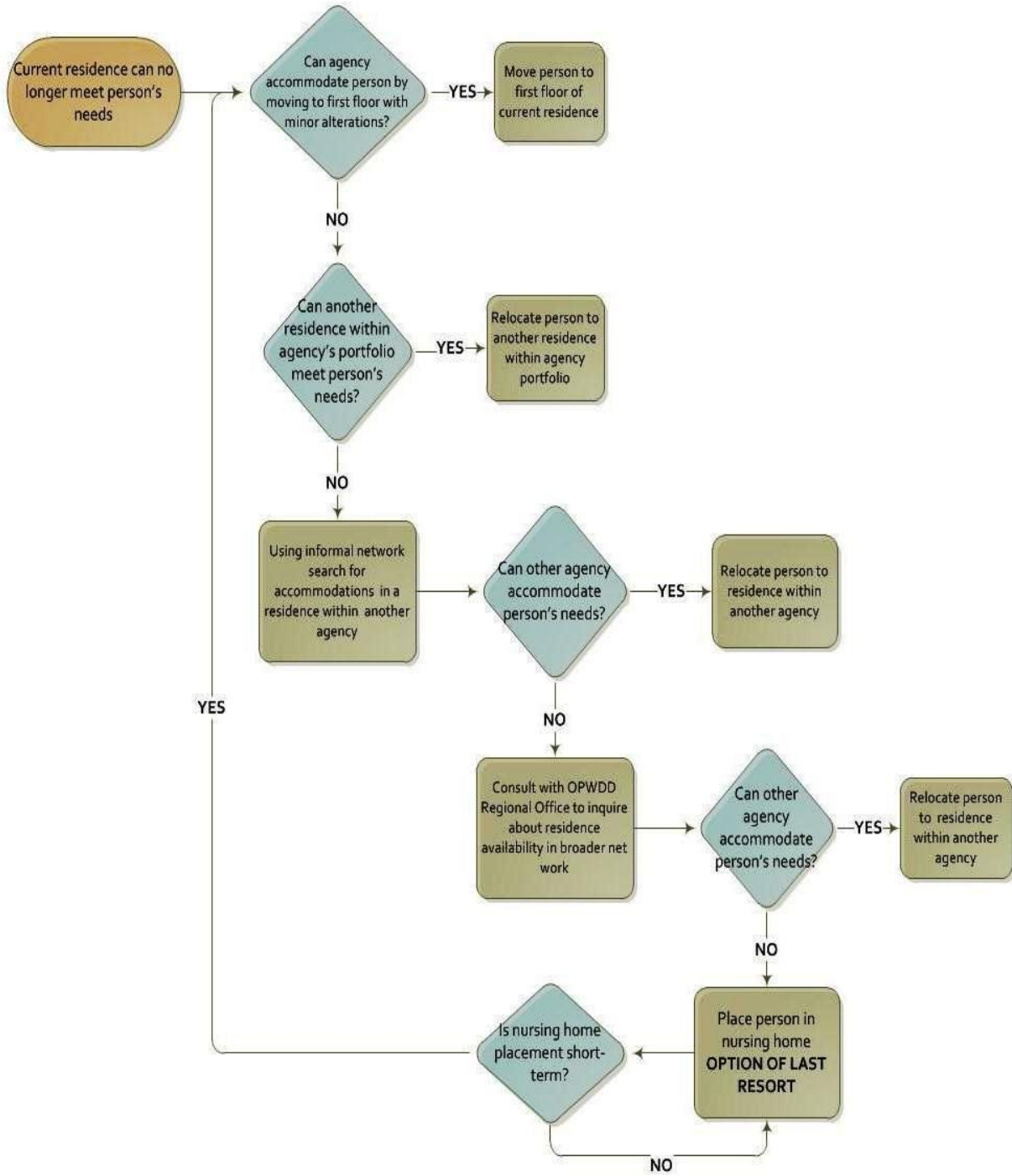
care affords the older person with intellectual and developmental disabilities the opportunity to age in place as the person returns to their home once they no longer require rehabilitative, nursing, or short-term acute care. Respite beds are also used to accommodate, temporarily, consumers who live in the community and whose caretaker needs a break from that responsibility for a short period of time.

We are very fortunate to have respite beds. I do not think other agencies are as fortunate. In my prior organization, we didn't have that luxury [of respite beds], so we very often had to send them to rehab, and they needed to remain in a rehab until they were able to either ambulate and/or be integrated back into their home safely.

Larger agencies that have respite beds available to use as swing space during an extensive renovation, have a clear advantage. Once the renovation is complete, the respite beds can be used for purposes that are more conventional.

Figure 3

Pathways to Placement



*Bureaucratic barriers*

Bureaucratic barriers pose enormous challenges when an agency negotiates alternative accommodations either within its own agency or by finding placements with other community service providers. Participants commented on three prevalent barriers. The first barrier is the *philosophy* that homes must include persons of similar age and interests. The prevailing belief is that the house will be more harmonious and easier to manage if the persons living together are of similar age with like interests. This belief stems from the *interpretation* of a federal regulation that states:

The facility must not house clients of grossly different ages, developmental levels, and social needs in close physical or social proximity unless the housing is planned to promote the growth and development of all those housed together.

However, in my opinion, this *philosophy*, as codified in the above federal regulation (42 CFR, §483.470 (1)a, is inconsistent with creating a normalizing environment since many families are multigenerational and inherently have a diversity of interests. The regulation limits residential placement opportunities for thousands of individuals with intellectual and developmental disabilities on wait lists in New York. The regulation also limits the placement options of those who have aged in place but later may require transfer to a less restrictive environment.

It is not really up to us to keep a person in or out of a nursing home because we can't. We cannot make that decision because we may temporarily move a person if we have a bed in one of our facilities that already is built up and is wheelchair accessible. Our decision depends upon who also lives in that facility, because we try to put people there who have the same needs, same level, same age, or close to that. Their interest in life is on the same level.

In a normal house in which the consumers are, of course, aging, the ones aging a lot faster than others, the one or two individuals who need a great deal more service. What is happening, I think, at the present time is that

that service is being pulled away from the other group of population that does live in the house, and I think that they are taking away from the normal running of the house for the other individuals.

The second barrier involves OPWDD's preference to keep consumers in the same borough where they currently live. For example, OPWDD will not approve a person's transfer from a group home in the Bronx, where they currently live, to a group home in Queens, even if the homes are in close proximity. Sometimes, these artificial and oftentimes illogical barriers restrict successful placements to more appropriate and less restrictive settings that are conducive for a person to age in place.

Many of the people came out of developmental centers that right from the get-go needed barrier-free facilities, but we know there's a lot of people in nursing homes who could be brought home if you had the physical facility to accommodate them. I have no choice at this point because I don't have the beds. Sometimes OPWDD is so involved that other agencies that may have them but do not want them....The bureaucracy with the five boroughs is very tough. A Queens bed is a Queens bed, and not something that a Staten Island person can use, and they just go crazy over this, which, I think, is ridiculous.

Lastly, Willowbrook class members have assigned to them Community Advisory Board (CAB) representatives who act as advocates on their behalf. These representatives, however well intentioned, tend to be averse to change. The CAB representatives often do not agree to whatever placement options an agency offers a class member. If, for example, the agency finds a suitable placement that is located in a different borough from where the person currently resides, the CAB representatives will try to block the placement, even if the consumer will be better accommodated in a group home that just happens to be located in a different borough. OPWDD's resistance to approving inter-borough transfers may very well be related to the anticipatory grief imposed upon them by the CAB representatives if the state were to approve of the

transfer, thereby reinforcing the notion that any transfer between boroughs is not a viable option. Situations such as these make for a less than smooth transition. It also extends the period of time before an acceptable placement is found. In the meantime, the class member's CAB representatives advocate that the agency hold the bed until the consumer finds a permanent placement, irrespective of the fact that the consumer cannot go back to their former residence since the home can no longer safely care for the person due to their changing needs. Therefore, the bed where they formerly lived remains vacant. This is unfortunate for both monetary and humanitarian reasons. The first is the financial ramification of an agency not filling a vacancy and therefore not generating the revenue necessary to support its day-to-day operations. The second, more humanitarian and moral consequence is based on the fact that conceivably the bed can be filled by any one of the thousands of people with intellectual and developmental disabilities from the State of New York who have a need for residential placement.

Our chief operating officer is on a vacancy committee that deals with these kinds of issues and so he's constantly sharing this information with them. And so we may have a little, or may not. We speak to the regional director [of OPWDD] about our concerns if CAB is tying our hands with not filling beds. And then individuals in the hospital and we know, we have one, we know we're not getting that. Our hands are still tied, and they say they work with us, but it is just a very long process. Once we actually had to hold a bed probably for a year or more.

Wherever there is a bed available is where somebody should go. Now with the person-centered stuff, with the community advisory board, it is becoming very, very difficult. By the same token, it is pointless to hold these people in nursing homes if they do not need the nursing homes or agree that after a certain point in time it is perfectly appropriate to keep somebody in a nursing home just as my mother may need a nursing home at some point. My mother probably would have loved a six-bed facility, but they don't exist for the nondisabled. It's really a catch-22 that they are in.

No, we have one now, so we have somebody in a nursing home currently who happens to be a class member on top of everything else. And everyone is aware, the DDSO's aware, that this person cannot come back to that particular site because of the lack of accessibility. And they're okay with it. It's just that CAB's preventing the discharge until we find appropriate alternate placement. So meanwhile, the bed sits empty, knowing that this person can't come back into it. That is where the fight is now.

They are resistant and, if it's a class member, it's almost like you're going up against a brick wall. It's almost like a holy grail. The state says, "Oh no, no, they can't, they can't [be transferred]. They just can't." No, they can and, yes, I can keep a bed. If a suitable bed becomes available in the future, I'll take them back, but there's a lot of rhetoric in philosophies as far as independence and the issue of isolation in an institution.

The bureaucratic barriers mentioned above seem, for some, insurmountable obstacles to a smoother and more common sense transition into and out of residential placements as a person's needs change. These bureaucratic barriers are often more difficult to overcome than the physical barriers that hinder a person's ability to safely age in place. Three thousand Willowbrook class members currently receive services from OPWDD. A worthwhile endeavor for the service provider network is to educate CAB representatives to better understand and accept life transitions as a natural part of aging.

## Financial Issues

*We are victims of our own success. As people age, the cost of care increases and our reimbursement levels decided so many years earlier no longer cover the expenses of those aging in place. (Newsletter)*

### Residential Development and Renovations.

If an agency decides to develop a new group home or renovate an existing facility, a great deal of time and effort is involved in obtaining the financing and approvals to move the project forward. OPWDD currently funds less costly (less than \$30,000) and less involved maintenance projects through voluntary maintenance funds and, more recently, through reserve and replacement accounts. OPWDD funds new development and major renovations by issuing a Prior Property Approval (PPA). In order for OPWDD to approve a PPA, a number of actions need to take place. For example, the provider agency must request from OPWDD a feasibility study. The feasibility study includes the:

- nature and scope of the work to be completed;
- estimated costs for the project;
- architectural schematic drawings of the proposed construction; and
- recommendations to proceed with the project.

OPWDD determines the dollar value of the PPA based on the feasibility study, OPWDD's maximum permissible threshold amounts for the type of construction requested, OPWDD's available resources, and other state and federal regulations. The length of time between the submission of a completed feasibility study and the issuance of a PPA cannot be determined in advance. In recent years, the length of time has varied

from a few months to more than a year. The major variables are the state's overall budget deficit and the governor's approach to balancing the budget.

Once OPWDD approves the PPA, the provider agency negotiates a construction loan from one of its financial institutions. Recently, securing loans, even with the state's promise to pay with a PPA, has been difficult due to the credit crisis that began in 2008. Once an agency secures the construction loan, plans are drawn up and construction of the facility commences.

After construction and final inspections and sign-offs are all completed, the provider agency submits a final expenditure report to OPWDD, which who then determines the final rate of reimbursement. Once the report is accepted by OPWDD, the provider agency converts the construction loan to a conventional mortgage. OPWDD assumes the debt obligations by adding the mortgage payments into the approved reimbursement rate over the course of the loan.<sup>1</sup>

In addition to the time and expense of embarking on major capital projects retrofitting an existing facility, there is also a disruption to the consumers who live in the residence. While a facility is undergoing construction, there are two options:

1. Consumers can continue to live at the facility if the construction involved is not too extensive and planned with great care, or
2. Consumers, more often, have to be relocated, from a few weeks up to one year, while their home is renovated, resulting in additional expense and disruption.

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<sup>1</sup> Center, J., & McCauly, L. (2011, October 24), personal correspondence.

Provider agencies must look for available space in hotels, nursing homes, or another facility that must meet or be brought up to code before it can house individuals with disabilities. This can stretch the period of construction even longer.

### *Vacancies.*

As mentioned earlier, a consumer who temporarily requires skilled nursing care or a short-term rehabilitative stay could return home provided that the home is barrier-free. However, when returning home is no longer an option and placement into an appropriate community setting is difficult to find, the agency tends to hold that person's *bed* until the person is successfully discharged from the inpatient facility into another more appropriate placement. The common practice of holding beds causes financial hardship on agencies.

Again, if they're in an IRA, we don't get reimbursed. If they're in an ICF, we do get paid but not for the one-on-one, so we're going to get the same rate as if they were in the house and, again, that can affect the finances.

When our guys go to nursing homes, the nursing home staff is not familiar with the disability, and so we think that they have special needs that we're used to dealing with and we can accommodate them so we think it's really important. The other thing, too, is we think it's important: Somebody's on a ventilator and she's awake and alert, the last thing we want to do is put somebody in a place where they don't know anybody. We are their family. That's how we really feel about it. I guess being small, we're able to do that.

The financial challenges related to vacancies in group homes are related to the provider not being able to bill Medicaid during a resident's inpatient stay since the nursing home, rehab, or hospital will be billing Medicaid for services rendered. The provider agency continues, however, to incur expenses related to its fixed costs of running its residence and for any additional staffing used to supplement the nursing home

staff, which, while not a requirement, is nonetheless a common practice among providers. The financial loss sustained by the provider agency is equivalent to the approved rate of reimbursement multiplied by the length of stay; this loss can amount to significant sums of money over time for holding a person's bed. It is not uncommon for agencies to hold beds for a year or longer, imposing tremendous financial pressures that only mount when multiple residents of a given agency require extended inpatient stays.

Any way we can have them come directly back here, we do that. In some cases, for example, we had someone who fell and had a real serious fracture. So in that case he went from the hospital to rehab and then back to us. This can financially affect the agency because if they're in a hospital and they're in an ICF, we're able to bill for those days. Once they go over to a rehab, we cannot bill for those days.

If they are in rehab for a month, it will impact the agency financially. We're not able to bill for that bed for the month. With the IRAs and given that the senior programs are IRA programs, it also impacts the agency financially because in an IRA, if you're hospitalized, the agency cannot bill at all. If someone is in the hospital for two weeks, three weeks, or four weeks, financially this has an impact on the agency.

We can't do the extras anymore because we have been brought down to break even. IRAs are in a large loss situation mostly because of our vacancies. We have high vacancies due to hospitalizations. Hospitalizations are something that we are struggling with now. We have severely struggled with it the last few years.

They have to be present in order to bill for that day unless they are going on a visit. You can bill for therapeutic leave, vacation, visits with the family, provided that they're in the ICF residence twenty-two days out of the month. But with the IRA, it becomes a problem with the hospitalization and billing.

In our case, what it resulted in is, for example, I have six consumers who are in nursing homes right now for an aggregate of 6.5 years. It has cost me over a million dollars because I can't take them back because the doctor's say that they need barrier-free beds. But by the same token, I can't fill the beds because unless there's an appropriate discharge plan, you can't use the beds.

As consumers age, hospitalizations become more frequent and due to the billing structure mentioned earlier, this adversely impacts financially since the agency has to contend with program vacancies that are not billable. OPWDD does however, provide a mechanism for agencies to appeal for reimbursements related to bed holds or vacant beds, but only if the agency has a cumulative deficit at year end and provides a justification, which backs up the appeal. As illustrated earlier, the rate appeal process is labor intensive for both the agency and OPWDD.

There's some talk that they're [OPWDD] not looking at rate appeals right now. But, in order to do a rate appeal, you have to show a loss across the board, across the agency. That doesn't always happen. But if you can show that you've had a loss at least across the ICFs or at least across the IRAs, then you can apply for rate appeal. I don't know how much they're paying attention to rate appeals given the economy and all that, but in the past, we have.

Well, we gave up on the appeals. OPWDD gave up on the appeals. We're frequently not within budget. We've looked a lot more at the efficiencies on the payroll. We've worked on that a lot to free up some of the dollars for the real work. But no, but even now, I mean, I'm just now comparing the actuals on both overtime, regular staff, temp staff, and I'm just [chuckles]...I'm just, I don't know if horrified or what, but I just...it's scary. But it is something that we're accustomed to do. We monitor it a lot, but sometimes it's a necessary part of the business, and we don't shy away from it and we don't feel that, you know, discharge someone because they needed a one-to-one or they need a two-to-one temporarily. Like I said, we make it our business to make sure they get what they need.

As mentioned above, it takes an extended period for an appeal request to run the bureaucratic gamut. Until that process is successfully completed, agencies, by default, subsidize their group homes. As consumers continue to age and become more medically frail, the financial impact only further intensifies the urgent need for agencies to develop more barrier-free residential options.

Larger agencies experience less of a financial impact because they can spread the loss over many more programs. Also, large-size agencies seem to fare better financially since

they have a diverse portfolio with many more programs to net out deficits against its programs that run surpluses.

Yeah, it goes across like one of our programs, like our thirty-bed residence, really supports a lot of the other programs. And that's what I guess the balance across the day habs, the IRAs, the ICFs—they sort of then come, so it's not so just the one may be in the hole, but that all of them aren't. So...if we just had IRAs, it'd be a different story. We would always run a deficit.

You have to run significant deficits in your programs to appeal, but appeals are nonexistent at this point. Many times we use resources within our own organization. We will shift resources from one site to another. We will take individuals who are salaried individuals and say, "We need you to focus your attention for this period of time with this individual with this program." For the most part, we try to utilize whatever in-house resources we can or community linkages.

Some of our programs run at a loss, but they are balanced out by the programs that run as a surplus. So we kind of look at all of our IRAs together and all of our ICFs together. We do not just micromanage one with the other, and as long as there is resources that balance out between them.

You still have to look at the agency at large that way....Not only are we large, but we are also diversified. We have medical programs. We have behavioral programs. We have the different levels between the ICFs and the IRAs, so if somebody really needs a higher level of one-on-one or a higher level of services, we can move them between an ICF or an IRA or an apartment, depending on what their physical and mental levels are. So having the diversity—we've actually had individuals who were dually diagnosed. We have center-based. We have community-based. We have a transportation company.

*Regrets, they have had a few.*

In the late 1990s through mid 2000s, OPWDD encouraged agencies to convert their ICF-DD residences to IRAs and to downsize the number of beds so consumers could

have more personalized residential options. In addition to increasing personalized options, OPWDD also realized that the conversion would provide the state greater flexibility with the way it managed the pot of Medicaid dollars that New York State received from the federal government under the HCBS waiver. Initially, the conversion of ICF-DD residences to IRAs made sense to agencies. However, as their consumers have aged and required greater support, the conversion for some agencies has proved to be a financially troubling move. Several executives regretted their decision to downsize their residences and convert from ICF-DDs to IRAs. The funding shift at the time of the conversion was budget neutral. However, with fewer consumers to cover, fixed costs combined with added clinical and staff expenditures related to more complex medical needs of aging consumers, IRAs. Once again, large-size, multiservice agencies fared better financially as they were able to reallocate resources across their diverse portfolio of residential programs.

Well, theoretically and philosophically it was supposed to be more person-centered, independent living, Kumbaya, that wonderful, everything is so wonderful. Then you unbundle the service, which made sense because in the ICF everything was bundled together. So you had a psychologist, you had a nurse and a speech therapist. Whether you needed it or not, that is what that house had. The money to pay for clinical services was within the rate, so whether Johnny needed it, it did not matter because housemates Marian and Frank needed it, so that's why you got it too.

IRAs were developed differently. You go outside of the program to get those services and you use your Medicaid card, so it's still Medicaid but from different angles, so that it's not all sitting in OPWDD's pocket because now that Medicaid bill, the Medicaid card, goes straight to DOH. And that's who's funding the clinics, right?

As I said before, you will have some programs, some homes that are more costly and their budgets will be impacted by the needs of the people there. Because we are a big agency, I think it would be very difficult to weather deficit budgets from so many former ICFs with now complex cases.

Even though clinical services can be accessed from the Article 16 Clinic, those services were not always accessible or appropriate for the needs of the individual. Many individuals received services regardless of the intended effect, as long as it kept the clinic in business. Several executives revealed that clinical and medical services were provided to IRA residents within the group home, an additional expense that was no longer covered in the IRA reimbursement rate. Had they remained an ICF-DD, these clinical services would have been included in their reimbursement rate.

So the money was coming from two different places, so it wasn't all sitting on OPWDD. That's probably one of the actual reasons why it is more about a funding mechanism, as opposed to philosophical, because many of the folks, once they made everything to IRAs, many of the folks who would have required an ICF level of care back in the day are now sitting in an IRA requiring the same things that they needed before and more. But it's no longer all-inclusive in your rate. You go out to different clinics. But some of that is so fragmented. I brought in-house some nurses, ABSS [applied behavioral sciences specialist] and some psychologists. Even though they may see a psychologist in a clinic, the psychologist does not do behavior plans because they can't bill for this, they can't bill for that. So now, what am I going to do with you? What are you going to do for this individual if you can't do counseling? Okay, he's nonverbal and he has no interest in counseling. What service are you providing? So at our own cost, you are bringing in [services]. So now starting to look a lot more like ICFs than it was meant to.

If you converted cost neutral, you thought you were keeping whatever that rate was, and you were. But the services are no longer happening out there, the clinical services. Now we're providing some of those clinical services and we're eating into that money that we thought we were going to score on. We are back to where we were before in terms of having to provide those services for the same amount of dollars, so it did not save you anything. Sometimes it even comes out to more. OPWDD has made such a mess out of it that it is hard.

Participants had thought that converting residences from highly regulated ICFs to less regulated IRAs which would accommodate fewer people in each home, appeared at the time, to be a sound decision. The reason agencies converted was based on the belief that IRA

reimbursement rates were more generous than ICF rates. The reason IRA rates were higher was because IRA residents, post conversion, would then be able to access clinical services from an Article 16 clinic, which, in turn, billed Medicaid, or Medicare directly for services rendered. Clinical services provided in an ICF however had been paid by the provider agency directly, because bundled into the ICF reimbursement rate was funding for clinical services. Over time, accessing clinical services from an Article 16 clinics became difficult for a variety of reasons. Agencies then had to absorb the cost of accessing these clinical services for their consumers that, out of necessity, were provided by salaried clinical staff. Any savings in reimbursement between ICFs and IRAs was then diminished. The billing methodology for IRAs, whereby agencies could only bill when the consumer was housed for 22 or more days in any given month, also contributed to the diminution of IRA reimbursement rates. As residents began to age and their medical needs became more complex, they had frequent hospitalizations that often compromised the agency's ability to bill for the entire month. The downsizing aspect of the conversions also had a negative impact on the finances of an agency. Operating a group homes for older people with high medical needs, with fewer of them to cover the fixed costs, is a less efficient model. This was the lesson several participant agencies had come to learn, albeit the hard way.

*Nobody Does it Better.*

A common agency practice is to assign staff to a hospital or to a nursing home for all or part of the time one of their consumers is admitted. There is a perception on behalf of agency staff that hospital and nursing home staff do not know how to properly care for persons with intellectual and developmental disabilities since doing so requires specialized skills. Direct care staff are deployed to the nursing home or hospital to be present in case the resident needs an advocate, and to inform caregivers of the resident's preferences, and to report back to the group home on the condition of the resident. The direct care professional provides companionship and a familiar face to the resident in the hopes of lessening any anxiety provoked by the hospital or nursing home admission. Agencies are prohibited from billing for the days a resident is hospitalized therefore assigning staff to cover shifts outside of the residence causes an added expense that often is not reimbursable.

Unfortunately, we did have a situation where somebody was on a ventilator and we tried with the state to work with them to let us keep her in the house. And they just wouldn't let us do it, so she is at a very nice nursing home in Suffolk. But what we're continuing to do even though we're not getting funded for it, we are sending staff people there twice a day to see her for about a total of six hours a day.

While they are in the hospital or rehab, we have one-on-one staff with them. Again, we do not get any additional funding for that. So you could say that impacts the agency financially because we are paying a staff person to be with that consumer around the clock.

Direct care staff is sent to the nursing facilities or rehab even though they are already staffed with their nurses as well, but so that we can get our feedback because at times the nurse may not tell us everything. There may be some things that slip through the cracks and also for the individual to see a familiar face, which always feels good. We try to find a staff who actually knows the individual that has worked with them. Say for instance, the hospital nurse says, "I noticed this behavior." We can say, "Oh, that's normal," or say what is not normal because they don't know

them. We usually send staff for one or two shifts, depending on the needs of the individual.

We send our staff to be with them, just to make sure that they are getting the services that they need, to make sure that they are being assisted with activities of daily living. They assist with everything and report any changes to us.

Often times, we do good or best practices to have some type of oversight, but it is not a long-term solution because it is a continued financial trade without any revenue to break even. I do not make money. I want to break even. I do not want to lose money, but sometimes it is unavoidable.

According to one nursing director, assigning staff to nursing home shifts should be time limited. Once the direct care worker educates staff about the preferences and the idiosyncrasies of a particular resident, the staff assigned to the home should be withdrawn since the agency is not receiving funding while the resident is hospitalized or in a nursing home.

Yeah, someone who knows them well, someone who knows them well to educate the staff there in the nursing home. "This is what he likes. This is what he does." Then, yes, provide a little bit of support, but then we have got to pull. They are getting paid for that bed, and they have got to be responsible unless I feel it is truly unsafe. But if the person needs a one-to-one, they need to provide it. They are getting the money for the bed.

To curb the financial impact of assigning paid staff, one large-size, single-purpose, secular agency is using volunteers, instead of paid staff, to sit with consumers while hospitalized and or in a nursing home. This is a viable solution if, in fact, the volunteer is familiar with the older resident. If not, then the justification for using volunteers, for anything other than financial reasons, is a faulty one, given the common argument that the resident needs "a familiar face" during their in-patient stay.

One of the successful things that we're also working on now is volunteerism, getting people to volunteer to cover the hospitalizations where we're not mandated by hospital rules or OPWDD rule to have somebody in the hospital with an individual. But, if an individual's in there and the hospital is saying, "You should have someone or no one can take care of them appropriately," so you're going to do it. As an agency, you're going to make sure that your men and women have the best supports that they can have. So we're working to beef up and build up our volunteer initiative specifically targeted at having people go to the hospitals, even if it's for a few hours.

It doesn't have to be 24-7, but if we can get those individuals to go during peak time when we have people coming off the bus and coming home, dinnertime hours, that type of thing.

Another large-size, single-purpose, secular agency is trying to strike a balance between using its staff to supplement hospital or nursing home staff in order to educate them on the nuances of working with an older intellectually disabled population while at the same time not substituting agency staff for hospital or nursing home staff.

We are trying to engage in dialogue with this hospital to look at—there are things obviously, if somebody has a special feeding need or communication needs, of course we're going to do that, but we can't be the babysitter. We are not there in lieu of hospital staff. I personally had conversations with their patient services in the medical department and even their hospital CEO. When you talk to them, they agree that it shouldn't be like that. But truth be told, it's different on the floor [hospital unit] when there's somebody [agency staff] there.

Another executive of a medium-size, single-purpose, secular agency with disproportionately fewer older residents than the other participating agencies, believes that supplementing nursing home or hospital staff is not a financial burden for her agency at this time, due to the agency's small size, and that it has fewer residents hospitalized or in a nursing home at any given time.

I would say it has impacted the agency as far as aftercare with surgeries like this. People needing one-to-one supervision for periods of time after a

surgery like this—sometimes up to four weeks—so I mean it has an impact on us. But fortunately, again, because we're small, it's not bankrupting us, which is a good thing.

Participants from five of the six agencies included in the study, appear to have a constant struggle trying to balance what they believed to be in the older consumer's best interest when they deployed their workers to cover in-patient stays, even when doing so is often at the peril of the agency's financial health.

## Workforce

### *Training and Supervision of Staff*

The aging of persons with intellectual and developmental disabilities has had an impact on organizations and their staffs that care for them, in a variety of ways. In response to questions about that the impact that caring for older consumers has had on their workforce, several study participants reinforced a greater need for specialized training, monitoring and supervision of both direct care and clinical staff. The complex medical needs of frail older persons require that agency staff learn how to properly care for those older residents who have more than one chronic condition, which is often the case with older people. Treatment of the more common chronic conditions include: diabetes management and insulin therapy; nutritional requirements and specialty diets for persons with swallowing difficulties due to stroke, paralysis, or other medical conditions; proper administration and tracking of multiple medications; assistance with mobility; correct fire safety and evacuation techniques; and appropriate use of medical equipment and assistive devices.

I can give you two examples of difficulties that we are having at our agency. I'm not going to say it's prevalent, but it is certainly something we are seeing with our older folks. Every so often we have a consumer with swallowing difficulties. One of our speech therapists is considered a feeding expert, so she'll go in and do a swallowing evaluation. She sends them out to whatever the appropriate clinic is, and then we'll have to modify diets, we have to provide increased training, choose staff, and all that.

There's more and more training needed all the time. It's more sophisticated training as our guys are aging and because the needs are getting more complicated or more comprehensive.

In our ICF for medically frail seniors, it requires a lot of staff training. I have two full-time nurses, eighty hours of nursing a week. It's not twenty-four hours, but it is nursing. It is most important to have nurses on staff

when a person is discharged from the nursing home. They have to do staff training, staff training, and more staff training. The discharge home should not necessarily make us increase staffing patterns. It's really a lot of staff training and a lot of staff support. You want nursing in there for almost every feed for the first three weeks at least.

Another issue is with the [poly] pharmacy, and these guys are on medication such a long period of time and, eventually, it's affecting the brain and it's causing atrophy and it's affecting their balance and their gait. We're seeing more of those issues here with the poly-pharmacy and it gets too complicated. Then we get them into a nursing home.

It's a training by speech person, then it's training by nutritionist, a training by physical therapist, and general training just to be patient. It's increased supervision. It's improving training. Yes, it's increase in monitoring and sometimes it's increase in staff.

*Job is More Physically and Emotionally Demanding.*

As care for older persons becomes more complicated and they often become less ambulatory and have expanded use of medical equipment and assistive devices, staff must be trained on the proper use of the equipment and the proper transfer techniques to avoid injury to themselves and to consumers.

And it's also training when somebody who was ambulatory becomes nonambulatory. You have to know how to transfer a person. It's a safety issue. It's also a fire evacuation issue involved that you have to address to make sure that the person will be able to evacuate on time in the evacuation.

The level of care, the type of care is different. It may get more physical. There's more lifting. You have to be trained in how to use a pulley lift if that person is in bed and can't ambulate, medication monitoring for the AMAP [Approved Medication Administration Personnel] staff because it's complicated. They have like twenty medications that they are on.

It's more complicated. It takes more patience from the staff and, of course, it's to recognize the problem, to deal with the problem, to treat the problem, and of course put the older person, who already has a disability

level and now they have additional problems—it's even more difficult to take care of them.

I think it's more challenging for direct-care staff and for house managers. If they are hired to work in a particular house from the beginning, they know who they have to deal with. Hopefully they're committed, remain loyal, and accept their responsibilities. Turnover is not a problem with these staff. However, when our people start to have aging issues or suddenly have a crisis, staff then have to deal with increased services all around, and I think it is very difficult for some staff to deal with. Consequently, we start to see more staff turnover. They look for less strenuous work elsewhere.

#### *Increased Liability of Service Providers.*

Several executives expressed concern that direct-care staff are given a great deal of responsibility and are often expected to operate outside of their core competencies, thereby creating a liability for the agency and putting the older resident at risk. Also noted were the unrealistic expectations on the part of OPWDD as related to the increased demand and responsibility placed upon direct-care staff.

No, we do not have nursing in our homes, even when someone requires oxygen. Oxygen is considered a medication, so the AMAPS are trained to administer the oxygen. Once you get to know the individual, you know when a person is coming down with something or has pneumonia. And if you do training and you put primers in place, it's doable.

They now have G-tubes and PEG tubes, and the nurses take care of all that. They do trachea cleaning. The state's mindset is to have your direct-care staff doing that. That scares me. It's frightening enough sometime. What I've done instead is hire LPNs to do that as a go-between. It's not a nurse but it's an LPN, and they're definitely trained to provide that type of service.

All of a sudden you have to give the person who gets diabetes insulin shots three times a day. If that's the case, we will use visiting nurses to do injections. I know that OPWDD says it is allowed, but I don't want our line staff to have to do the insulin injections. It's too much of a liability. We might even increase the registered nursing staff, depending on what the needs of the consumers are.

One chief financial officer from a large-size, multiservice, secular agency discussed the human resource liabilities related to serving medically involved residents. He reported an increase in the number of staff injuries and workers' compensation claims at his agency due to the increased physical demands of caring for older, more medically complicated older persons. Others discussed the emotional challenges experienced by staff when caring for persons who require a higher level of care.

Through my involvement with our human resources department—providing care to more involved individuals has affected the staff as it relates to physical injuries. I know this because I'm involved with the workers' compensation, so from a cost perspective and from an employee perspective, we have more people going out on workers' compensation or leave because of back problems, elbows, this having to do with lifting and straining of body parts. We have leg, arm, and back issues that have risen. Now that we talk about it, it is something to seriously consider.

Some people have issues then they come to work where they deal with more issues, and not everybody can tolerate that intensity. That's why supervision is very important. Not only for direct-care counselors. There is also a need for managers to have a presence, so they can intervene in a situation and redirect at times. If the person is not able to handle a situation, the manager can take over and tell the person, "you can just go ahead and do something else today."

Study participants reported a greater need for hands-on support from senior-level staff, which is necessary not only to supervise and train staff, but also to model proper techniques and to problem-solve when difficulties arise. Senior staff providing more *hands-on support* and experiential training helps mitigate the increased liability that providing complex medical care imposes on voluntary service providers.

When our residents become more medically compromised, there is more hands-on stuff with the nurses and with the residents. I mean that there is a

richer staffing pattern that's required. So training is different in that is much more sophisticated training for the staff and more training for the nurses. It all poses a greater liability for the agency, so we make sure that everyone gets trained.

I honestly think a lot of that [resistance] is related to fear of not knowing what to do. But once we reassure the staff and they get some training, they are more likely to cooperate. Information is powerful. I always explain to them that whatever medical type assistance they are expected to provide can be a stepping-stone to becoming a nurse's aide or a nurse someday.

We're educating and telling direct-line staff, "if you're ever unsure, you call the nurse, you call me, I'll come over." We have to explain to them about the situation that the individual is in and that we feel it is important for the individual to continue to live here. That they need this feeding tube for example, since this is the only way for them to stay alive and they need to get this nutrition, just as if you would feed the person at the kitchen table.

Then once they're properly supervised, then you pull the nursing away a little bit and you have them do spot-checks a couple times a week until the system runs well and they know what to look for, what to report, what's an emergency.

Two large-size, single-purpose, secular agencies took a more reactionary posture to increased training needs that are necessary to care for their older residents with complex medical needs.

If, for example, somebody comes home from the hospital on a Friday afternoon with a new G tube or a new something else— colostomy bag—you have to gear up quickly. The nurse is really going to be supporting the direct-care staff the minute the person returns home because there's so much training that needs to go on with G tubes that all of the return demonstrations and working with staff on both the medications and food. So they would be part of the component of helping to provide those supports. We might switch off staff. You get a couple of them in-serviced, get through the weekend, work on getting the rest of them in-serviced, and go from there.

Another large-size, single-purpose, secular agency reported that it plans to hire an expert in aging issues to develop specialized and individualized trainings for clinical and nursing staff. The executive also expressed the importance of having a flexible and more nimble workforce, so that

the agency can easily deploy staff and readjust staffing patterns as the needs of their consumers change.

What we're looking to do is seek the assistance of a gerontologist to specialize our medical areas to the needs of geriatrics. We're going to be contracting, hopefully in the early part of next year, with a gerontologist. We're actually in the program-planning phase and consulting with a gerontologist as to what are the specialized trainings that our clinical and nursing staff should have, because we have RNs for the most part, but it doesn't mean that they specialize in gerontology. So we're going to be looking to send them to training.

There's a lot of general overview-type training that our staff get during orientation. They are not learning it in-depth. They're just seeing it and hearing about it. Then, depending on the house and the people you support there, the nurse will work those staff and the manager to provide them with in-services on the procedures that pertain to the need of those living in that residence. So, let's say somebody in that home is a diabetic, has a catheter, whatever the different needs are—the nurse would be providing that training.

A chief operating officer of another large-size, single-purpose, secular agency espoused the benefits of implementing a uniform training curriculum for its nurses assigned to teach the support staff on how best to care for the older adults who are medically frail. Also stressed was the need for staff to be observed and evaluated by having them demonstrate whatever skill they had been trained.

We offer a few different types of specialized training on aging. One course is dementia specific. We also have specific trainings for conditions that are common with aging clients. We have curriculum and teaching plans for each of those conditions. That's something we developed a few years ago to standardize what every nurse trains on. Part of the decision to do it uniformly was because we are big and cover a large geographic area. There are a lot of homes to cover and be accountable for.

Training isn't necessarily the only thing. You can train and train and train, and then go back and test someone, and they'd pass the test. But when they have to actually do it a week later, they don't pass. We have to have a lot more performance-based training now because the training itself is

more complicated and intense. Even new staff go through our training program, they come back and they have to deliver. They have to do performance-based evaluations for our different training instructors and clinical facilitators to prove they know what they're doing.

The agency executive director of a medium-size, single-purpose, and secular agency asserted that the aging of her consumers required a workforce with a different skill set. She spoke of the pervasive problem that she had with her direct care staff in the past, claiming they often lacked judgment and critical thinking skills.

Well, I have found that because the aging population requires more attention—and I think you need better judgment—and I found that some of the judgment on behalf of the staff was just not where I wanted it to be. And so there were things that were being overlooked. And again, they were limited in terms of their education level.

In order to ameliorate the issues noted above, one executive director initiated a pilot project that involved increasing the credentials of the agency's direct care staff by requiring a college degree, changing the job title to a loftier one, and increasing the compensation rate by 30 percent, on average. According to the executive, the pilot was successful, as staff were able to think critically, make better decisions, and provide better care to their aging consumers. This change in hiring practice was also cost-effective for the agency because fewer staff did more of the work, provided better care, and were more reliable with showing up to work. The pilot project was extended and has since been integrated into standard practice that was in effect at the time of the interview.

We weren't sure how the pilot was going to impact the agency financially, but as it turns out we actually are saving money because they're more responsible workers. They're not calling in sick, so we do not need tons and tons of overtime. They don't call in every minute with excuses that they can't come in or that they're sick. So, as it turns out, we don't need as

many people on shift. For example, our ICF [Intermediate Care Facility] for ten people, and we would have seven to eight direct-care people on a given shift. Now we have five or six habilitation people on shift. I'm getting more work done, providing better services, with fewer bodies who are better paid. Everyone benefits.

## Programming

*What is old is not always new again.*

During the time the study took place, all six participating agencies had not developed programming exclusively for older adults. Each agency sends their older consumers to community-based day habilitation or day treatment programs for persons with intellectual and developmental disabilities that are either administered by their own agency or sponsored by another agency. Two participating agencies that operate day programs, noted that staff tend to segregate older people into one activity room within the day program. Their rationalization for doing so was that older consumers could then be with their peers. Reported was the tendency to assign staff most adept with dealing with aging issues to cover the activity room with the older participants. They reported no qualitative difference however, in the actual programming from that of the general population of persons with intellectual and developmental disabilities who regularly attend the day program.

Okay. I'm going to say most of them still go to a day program of some type. Not every single person, but most if they can physically, medically get there. We have a number of programs that are more geared to people that are seniors. Some of them are the very active, out and about the community seniors, so that's not going to be the frail individuals.

I'm not sure if it's any different. I mean it's needs-based and what their choices are to do. But their choices happen to be more things that are geared towards people that are seniors. But that involvement isn't that different in other programs, it's just more the peer grouping and the supports that are there. We've had to move them. They're in barrier free locations now. They weren't originally. There was a senior program that they had stairs. So, we ended up moving them to a different program site.

Unfortunately, I would like there to be more changes in program in terms of providing more appropriate activities for the elderly. We've also purchased a handicap accessible van so that if someone had difficulty getting into the van, they're able to use a wheelchair. It has a wheelchair lift. We've done that.

The executives of a mid-size, single-purpose, and secular agency spoke of the practical ways in which community outings have changed because their older consumers are no longer physically able to participate in strenuous activities or in ones that may present a danger to a person who is physically or medically frail.

Again, we're selecting activities that are geared for the older population. Such as, they would probably go to a movie before they would go roller-skating. Things like that. Some of our guys will go tubing. They may just take a ride Upstate New York to do some sight-seeing, go see a show, a rodeo, something along those lines. We're very specific in choosing activities that are also age appropriate and that are conducive to whatever limitations they may have because of the aging process.

Well, some of the guys who used to go roller skating don't go roller skating [chuckle]. Then, again, at events we sat wherever we got tickets, not for the people who need walkers, and wheelchairs, obviously we've made those adjustments. And as far as activities, active treatment goals and activities, they've pretty much stayed the same.

A chief operating officer of a mid-sized, single-purpose, faith-based agency, commented on the ways in which the participation of frailer older consumers has been curtailed at his agency's day programs.

We have an in-house program in which the consumers participate in eight service areas on a daily basis. However, the individuals who have progressed rather severely or who have aged with a great deal of dementia, they stay within an individual room usually, and the staff people there are trained to work with the elderly population. That does not mean that they're isolated in particular in the room, but we're able to accommodate them at a greater skill level than if they participated in several service areas on any given day.

*Retirement from Day Program.*

Several executives expressed a preference for allowing seniors to retire. At the time the study took place, this was not considered an option for older people residing in group homes. Unless a person was severely restricted in their capacity to physically attend day program, he/she continued to attend most days.

I think the one frustrating part that we have no control over is that we would prefer to keep our older people with us all day as opposed to sending them out to a day program because there, I don't think there's that much diversity in terms of the programs that they have but is just not normal for people in their 60s and 70s to get up at 5:30 in the morning and go to a day program. To me, that's not a normalizing. People need to retire at that age.

We have been looking at the day services that our older folks currently attend and we're really not completely satisfied with the programming that they get. We also think that our older folks should have the right to retire from going to day program so what we've kind of done is sometimes we work with the day programs to let our guys go in a little bit later or leave a little earlier. They day folks have to be there a certain number of hours for the day program to bill so they often give us a hard time.

Alternatively, several executives expressed their preference to keep older persons at home and stated that they would have staff provide activities at the person's group home, if OPWDD would support and pay for the additional staff required with such a model.

I know of no regulation that specifically prohibits an older person from retiring from day program; However, if there is no funding for alternative supports when a consumer does retire, agencies will continue to send people out to program because they would be at a fiscal disadvantage if they did not.

We don't know if that's going to happen but we do feel, as an agency, that when it comes time and the guys don't want to go to day program any more, we will support them at the home and provide active treatment for

them throughout the day but we won't get paid for it because staff would be from residential.

We have been trying to work with the state to open some kind of day services or to open a program without walls for our older and medically frail people but so far, they have not been in favor of that.

A significant problem is that the way OPWDD is structured, they do not allow for retirement so if these people, who used to go to your day programs, are forced to spend 24 hours a day in their residence, there's no finances for the day component of that and so it's going to be horrifically expensive and in a tight economic time, that's going to be a real, real problem.

Once again, the executives asserted that OPWDD had no grand plan to develop programming for older adult consumers with intellectual and developmental disabilities. Rather, OPWDD's focus, in recent years, has been on transitioning young adults who have aged-out of the foster care system or have aged-out of their school programs that were located out-of-state.

Agencies like ours have had to change the focus to accommodate the aging population, but I don't believe the state has kept up, and I believe their focus is not on the aging and they maintain a state of denial about it. They continue to focus on getting younger people who are transitional people from school programs. That's their focus and I think the funding hasn't gone into developing what needs to be developed to accommodate older people.

I think OPWDD is so caught up with just trying to survive in terms of the economy. For the last two-and-a-half years they haven't really – I know that the aging population is very important to them, and that they would really very much like to service them, but I think because of the amount of pressure that they have at the present to cut continuously funding that they can't even come close to what their goals are in servicing this population.

An executive from a medium-size, single-purpose, secular agency also cannot afford for her older residents to retire for all the reasons mentioned above. However, she also stated her preference for more recreational programming, if and when OPWDD provides the extra funding for staff and program support for those retired from traditional day programs.

It would be my choice to provide programming for them here where they can do those extra activities such as go to more movies or go to community events, recreational centers, senior citizen centers where there are activities for them to be involved in...I feel I could give them a much more fulfilling type of life during the week than they're receiving. I'm hoping that that will change one day because I think if they were able to fund the provider and keep the elderly at home then we could design very nice recreational programs for them.

## Medical Issues

### *Over-Reliance on Emergency Room.*

All of the participating agencies care for medically involved older consumers to the extent that they can do so without compromising the health and safety of their consumers. Older persons of all abilities tend to have a number of chronic conditions that require frequent medical appointments and diligent follow up for medical testing, coordinating specialty care and sick visits. Older persons in residential programs have access to nursing care but rarely is a nurse available twenty-four hours a day, seven days a week. The participating agencies have protocols in place to triage medical-related emergencies; however, consumers are frequently sent to the emergency room for a medical consultation that just as easily could have been done in the residence by a qualified medical professional, if one were available.

Our agency only provides twenty hours of nursing in our homes. Our people get, at most, 30 minutes of nursing care so when something is not right with the consumer, they go to the emergency room, emergency room, emergency room because, if the nurse doesn't see the situation or see how serious it is, most of the time she will send us to the emergency room, especially on weekends when the doctor's office is closed. It's her license on the line and OPWDD is always looking to see that care was provided and that consumers are not being neglected.

At the time of the study, the pervasive practice was for agencies to err on the side of caution by heading off to the emergency room for both serious and benign events in order to avoid getting a citation from OPWDD for not getting a consumer timely medical attention.

*Access to Quality Medical Care.*

Executives of two of the six participating agencies (medium-size, single-purpose, a faith-based and a secular agency) placed significant emphasis on their ability to access good medical care even though many specialists have been reluctant to treat the intellectually and developmentally disabled population because of their behavioral issues and the person's lack of autonomy with following through with aftercare.

The health and safety of our individuals is our priority. Even small little things, we're going to make sure that it's addressed and taken care of and if we can't, we're going to find someone who can assist us in making sure that it's done the right way. They get taken care of by the best doctors since our executive director knows them all since he has been around for a long time.

We don't send our consumers to just any rehab or clinic that is in New York. We pick the best of the best from our understanding of who is familiar with this population, and we have a good relationship with.

An organizing principle for one participating agency, according its executive director who is also a nurse by profession, is a focus on accessing good medical and preventive care from a pool of private doctors with whom she has cultivated relationships with over the years.

We do have a medical model because of my background [as a nurse practitioner]. We have all private doctors, cardiologists, nephrologists, ophthalmologists who we follow up with very carefully with all our consumers, especially since they're not really able to communicate if they're feeling ill, if they have pain.

We're very selective. We just don't to any clinics. We try to select doctors who are experienced with the elderly and with our type of

population and we've had people that had open-heart surgery. Our people go for colonoscopies so once they reach a certain age, just like we do when we get to a certain age, we're required to have certain tests done and we do the same. The women go for a mammography after age 40. They go for colonoscopy after age 50 and whatever's indicated. We do extensive follow up, especially our medically frail.

This same medium-size, single-purpose, secular agency also cared for the fewest number of consumers as compared to the other six participant agencies, therefore the executive director was able to get personally involved with each consumer. She personally ensured that each consumer had an annual physical, as well as other age-appropriate preventive care, such as mammograms, colonoscopies, and eye exams. In terms of accessing quality medical care, residing in a much smaller agency (categorized as medium-size for the purpose of the study), clearly has an advantage due to the personal attention and intimate knowledge the executive staff have of every consumer the agency serves. Having an executive director with a medical background and who takes a personal interest in each of the consumer's medical care, are also contributing factors to its ability to access what the executive director claims to be excellent medical care.

Because we're such a small agency, I'm able to assess the needs of the individuals. I think when agencies are large, people tend to get lost in the shuffle. In situations where somebody has a particular need, but because there's so many people, sometimes the person's need goes unnoticed. I think that our being small, as I said, we're able to assess needs a lot quicker and can be more effective at addressing those needs. If I had twenty-five programs, I don't think I'd be able to provide the same attention as I can here. I have people working for me of course, but I think because we're small, it gives me that opportunity to just be so much more involved in all aspects of our individual's lives.

Only one of the six participating agencies operated a residence designed specifically for medically frail older people with intellectual and developmental disabilities. Two participating agencies had planned to develop such homes for the medically frail by converting their existing

ICFs. These projects were put on hold by OPWDD for several years due to the economic downturn. One of the homes is now scheduled to open in the Spring of 2013. Another, single-purpose, midsize, faith-based agency had also planned to convert an existing residence into a home for the medically frail, however, once the financial crisis and subsequent budget cuts went into effect, OPWDD would no longer support its proposal. The agency's board of directors also withdrew their support of the project. According to this agency's chief operating officer, the consensus of the board was that the cost of care was too expensive and had the potential to put the entire agency in financial peril. This faith-based group was naturally risk-averse and my impression is that the agency's executive leadership as well as their board of directors look to OPWDD to take the lead to develop programs for the older consumers in their care.

Probably two-and-a-half, three years ago, we had planned to change our largest facility that which now accommodates eleven individuals into a care facility for our medically frail. We planned nursing and medical around the clock but the project never went through because cuts were coming so the DDSO turned it down. It was very clear that cuts were coming, and they were not able to financially support such a facility. I do know that [XYZ] agency has two of them; one here in Queens that's right near our day rehabilitation program, and the other one in upper Manhattan. We were going to do a very similar model, and thought we could have filled that facility with ease. However, they just found it just to be too costly, and that at that particular time our board could not support the initiative without OPWDD's support.

To my knowledge, two well established organizations who did *not* participate in the study have opened within the past two years, homes for older medically frail people with intellectual and disabilities. These homes, located in the downstate area, have twenty-four hour nursing care, seven days a week and are in high demand. In order to qualify for admission, a person must be otherwise eligible for a nursing home level of care. My myriad attempts to gain access to these

programs went nowhere. However, one of the six agencies that participated in the study had been operating similar homes for medically frail people with intellectual and developmental disabilities, for the past twenty years. In the following section, I presented as a case study, this large-size, single-purpose, agency's homes for the medically frail. This agency offered a model of care that exemplified what I considered to be, a practice with great promise. These model homes were smaller and less intensive than skilled nursing facilities, in addition, these barrier-free homes had a level of nursing services, technical and medical support that would be difficult to replicate in traditional group home settings. The model homes described in the following section were assigned pseudo-names: Buena Vista Home I and Buena Vista Home II.

I visited the homes on two occasions in April of 2011. During these visits, I toured the facility, was introduced to the residents, and observed the staff as they went about their day caring for these men and women with high medical needs. I also spoke with managers, nursing supervisors, staff nurses and several direct support staff. I did not conduct any formal interviews on these site visits. The staff understood that I was there to tour the homes and that I, like many other agency administrators who visited in the past, was considering developing a home for medically frail people with intellectual and developmental disabilities hence my interest in their model programs. The staff of the homes spoke openly and enthusiastically about Buena Vista Homes and of what they considered to be *best practices* in caring for the medically frail.

#### Buena Vista I & II– Homes for the Medically Frail

The homes are located in a rural area in upstate New York where manufacturing leather goods was the mainstay until business owners moved jobs overseas to take advantage of cheaper labor costs. Businesses closed and many the Victorian style homes indigenous to the area were

boarded up, as their owners could no longer afford the upkeep and their occupants moved elsewhere to find work. This former thriving county in rural New York was in a depressed state and an agency that has served persons with intellectual and developmental disabilities since as far back as the early 1950's was now the largest employer in the county; Wal-Mart was the second largest.

The sponsoring agency of The Buena Vista Homes, started when a small group of parents came together because they were interested in improving the lives of their children with mental illness and mental retardation. The agency continues to be led by an active parent board. Buena Vista Homes offer a wide range of services for people with intellectual and developmental disabilities and their families through its diverse portfolio of programs. Its 1,500 employees cover a 500 square mile catchment area in western New York.

Twenty years ago, Buena Vista's sponsoring agency proactively formed an Aging Committee that continues to convene its clinical, nursing, support staff and managers every month, to discuss the needs of their aging consumers. The committee also coordinates trainings, conducts outreach to community health centers and long-term care providers, and partners with the local Area Agency on Aging (AAA). Buena Vista offers training throughout the year to all agency staff on aging related issues. All agency consumers aged 55 and older, as well as those age 45 or older with Down syndrome, receive a comprehensive assessment annually to identify any age related changes in "cognition, behavior, ability to socialize, verbalize or otherwise interact with others". Those needing further testing and evaluation receive the appropriate follow up and, if necessary, individualized service plans.

On the agency's main campus, in close proximity to the agency's administrative offices, are the Buena Vista Medical Homes I and II, for persons with high medical needs. The homes, both

one-story brick barrier-free structures, are mirror images of each other, and that are connected through a breezeway; However, they are operated as separate homes, each having its own complement of management, direct care staff, psychologists, psychiatrist, occupational therapists, dieticians, licensed practical nurses (LPNs) and registered nurses (RNs), and also have separate operating certificates. Each home is staffed by at least one RN around the clock, seven days a week. Staffs are crossed trained so that they can be easily redeployed when there are staff vacancies and shortages.

The interior structure of the medical homes is “home like” even though they have such things as overhead tracking for privacy curtains throughout, various lifts and other contraptions, as well as chairs that recede back into walls or ceilings when not in use. Throughout each residence, there are Hoyer lifts, crash carts, walk in showers, bulky adaptive equipment, scooters and customized wheel chairs. The bedrooms are situated in a circular fashion with a common corridor making monitoring easier. Each home can accommodate up to twelve people. The criteria for admission is the person must be assessed to need twenty-four hour a day nursing care, need ongoing assessment and observation. A person does not need to be older in order to live in a Buena Vista Home. However, given the nature of the home, the majority of residents are older. At the time of the site-visits, 20 of the 24 persons living at the homes were over the age of fifty.

The Buena Vista homes are located across the campus from a public hospital, which fosters strong collaborations with the hospital staff and gives them the ability to triage cases more effectively. The staff boasted about their never having to, during the last 18 years, send any person from Buena Vista Homes to a nursing home. When a resident has a medical emergency, they are not automatically sent to the hospital emergency room. Instead, the nurse treats the person or consults with a medical doctor who examines and cares for the resident at the home,

thus avoiding a trip to the hospital emergency room. In the event the person needs to be hospitalized, the doctor circumvents the emergency room by directly admitting the person to the hospital, located in close proximity to the person's home. According to the agency's chief operating officer, Buena Vista Homes has evolved over the past two decades and her team of fifty-two nurses provide expertise and support not only to the residents living at Buena Vista, but also to the to the eighty other IRAs and ICFs the agency sponsors in the community, where the numbers of older consumers continues to grow.

We have not placed anyone in a nursing home in 18 years... Over the years we have continually evaluated our supports, and made needed changes. Those changes include staffing, clinical and nursing support, training, and working with other aging providers such as home care agencies. Having the 24 hour nursing and enhanced clinical services has been extremely valuable and has made it possible to support needs that would otherwise require a nursing home.

Compared to the many skilled nursing facilities that I have been acquainted with over the years, I felt that there was a qualitative difference in the way the staff of the Buena Vista Homes worked with, valued, and cared for the older persons within the agency. The staff, individually and collectively, exuded a strong sense of ownership and responsibility for the well-being of the people in their care. The residential manager was clearly the person in charge. Staff coordinated all aspects of the person's care, and regardless of rank, both professionals and paraprofessionals respected each other and worked as a team to provide care for these medically frail residents. The program had many systems in place that had been developed and refined over the past twenty years.

According to the executive director, the agency invests in their workforce by providing them with a career ladder. One example of how the agency invests in staff development was when the

agency collaborated with a local community college to offer its employees, a program for them to become licensed practical nurses, free of charge to staff. This helped the agency fill, according to seniority, vacant nursing positions since there was a nursing shortage throughout the state. Forty employees had taken advantage of the opportunity and became LPN's. Three of them left to work for the local hospital but eventually returned to work at Buena Vista when a position opened up.

According to the agency chief operating officer, the staff turnover rate is very low. There are three factors that may contribute to the low employee turnover. The first is that their employees are hired as part time, per-diem workers, and after a period of time, are offered a permanent position, but only if they do a good job, thus weeding out any workers that are not capable or willing to live up to the agency's standards. The second factor is the high level of unemployment throughout the region where the agency is located, therefore there are few alternative employment options. Once offered a permanent position, staff tends to stay and work for the agency, some for their entire careers. And the third factor is the agency, being very large and having a wide catchment area, affords staff the opportunity to move up the career ladder rather quickly, if they are motivated to do so.

Even though it would be difficult to replicate all the conditions that make the sponsor of Buena Vista Homes the employer of choice, there are some best practices that other service providers that can be replicated such as its medical home and a commitment to develop its workforce so that they too can better care for their older, medically frail consumers, and offer them the best life possible.

Providing such a high level of care with enhanced supports for older persons with intellectual and developmental disabilities is quite costly. Even though enhanced supports most likely costs

less than providing care in a skilled nursing home, the cost is still much more than your typical IRA or ICF rate would cover.

Having the 24 hour nursing and enhanced clinical supports offered at Buena Vista I and II are currently operated at a deficit and there is no evidence of this changing. Most of the people who live there have extremely intense needs and the staffing and clinical/nursing supports that are higher than ever. While this model has helped in so far as it prevents nursing home placements and offers individuals with high needs a home with the supports they need, the financial impact of maintaining this model is significant.

If funding levels are, in fact, not commensurate with the true cost of providing this intensive level of service, then this model is not a financially viable option for most agencies, regardless of the agency's size, affiliation or complexity.

## Chapter VII. Summary, Conclusions, and Implications of Study Findings

Older adults with intellectual and developmental disabilities are living longer, thereby affecting the human service organizations that provide care for them. The study has described the challenges voluntary agencies experience as they serve a growing number of older adult consumers. The focus has been on the adaptive responses these agencies have made relative to the following prescribed themes: physical plants, health and medical care, staffing, finance, and programming. Six voluntary agencies that serve consumers with intellectual and developmental disabilities in New York State were included in the study.

Twenty-two in-depth interviews were conducted with executives and senior staff employed by the six agencies. Data was further triangulated through direct observation, review of pertinent agency documents, web sites, financial data, and journal entries. The theoretical and conceptual constructs of the theory of successful aging as well as the organizational theories of structural inertia and resource dependency informed the study. Ethical considerations were mitigated throughout the course of the study by reinforcing with participants the voluntary nature of the study and reminding them that they could withdraw from study at any time, even well after interviews took place. Data was stored and coded in the qualitative software NVivo9. A cross-case analysis was conducted to determine similarities and differences between medium-size and large-size agencies; single-purpose and multipurpose agencies; and faith-based and secular agencies, relative to their adaptive responses resulting from serving a growing number of older people.

### Limitations of Research

The limitations of this study, such as researcher bias, were minimized through peer review of interview transcripts and the independent coding of data. Transferability of study findings was enhanced by using maximum variation in the sample of agencies that covered a wide geographic area in New York State, and that met the pre-established criteria in regards to size, complexity, and affiliation. Reliability was enhanced through reaching saturation in terms of participant responses related to the prescribed and emergent themes. Limitations of the study included the small number (6) of cases that were included in the study and the narrow range of participants in the study since only executive and senior level staffs were interviewed. There was only one faith-based agency, hence comparisons could not be made between secular and faith-based agencies, therefore, only pure data could be analyzed. Other limitations were attributed to having only one participant agency that serviced a rural area, exclusively. Two of the six participant agencies covered only suburban areas, while three agencies served a combination of urban and suburban areas. Given the constraints of their respective catchment areas, participant agencies did not have opportunities for housing or program development that entailed having a presence in a rural environment.

### Role of Agency Characteristics

As mentioned, one faith-based agency participated in the study. Therefore, the data gathered from this particular agency may very well be idiosyncratic in nature rather than reflective of the wider population of faith-based agencies that serve older persons with intellectual and developmental disabilities. While having acknowledged this limitation, I believed that documenting my impressions of this agency's responses was also important. Nonetheless, I

caution against any suggested linkage between the agency's responses with the agency's religious affiliation.

As reflected in the interview findings, the faith-based agency responded reactively to events related to individual consumers who were older but responded passively to the growing number of aging consumers in their care. This agency's executive director tended to follow the "path of least resistance" by permanently placing older residents in a nursing home instead of making the environmental modifications that may have very well prevented whatever event prompted the nursing home stay to begin with. When OPWDD thwarted the agency's plans to right-size and renovate one of its existing facilities, the executive did not challenge OPWDD's decision to halt its plan. Other agencies included in this study found themselves in similar situations, but instead, they challenged OPWDD to reconsider their plans. When the economic crisis abated slightly, OPWDD eventually issued prior property approvals (PPAs) that re-started these stalled projects. There may be alternate explanations for the faith-based agency's response of accepting OPWDD's decision and then abandoning its plan to right-size a residence. Alternate explanations could be that the projects that the other agency referenced were new development or they may have involved retrofitting existing structures, the latter being more involved and costly and the former being a more attractive option for OPWDD and for providers. Of note, there were no references in interview transcripts of the executives from the faith-based agency of any moral obligations or that their mission propelling them to act, or not.

Large-size agencies had several advantages compared to medium size-agencies. Larger agencies had a greater number of homes with which to move people around when they could no longer accommodate a resident due to age related constraints. On the other hand, larger agencies

had a greater number of individuals that needed to be moved around, therefore any advantage due to its relative size, could be cancelled out. Large-size agencies also have a financial advantage, based on their having more group homes with which to net out any budget deficits thereby minimizing the impact of increased expenses related to serving a greater number of older consumers with higher level and more costly care needs. Another advantage that larger agencies have is their robust infrastructure that supports such things as research and development, quality assurance, and the human resource departments that assist with staff recruitment, and a planning office to help with the development of innovative responses to the growing number of older persons. One such example, detailed in an interview with an executive of a large-size agency, was its use of volunteers to accompany older consumers when they were hospitalized or admitted to nursing homes. The volunteers had been recruited by the agency's office of volunteer services, saving the agency money on the cost of substituting paid staff for volunteers. Another advantage is that larger agencies are more likely to have the political clout and to use it to influence policy and funding decisions - a clear advantage for any agency dependent on government funding. Comparatively, executive staff of medium-size agencies have ample opportunities to interact directly with consumers and therefore they gain a better understanding of their consumer's needs and through the authority vested in their high level positions, have a greater motivation and ability to address those needs.

Single-purpose agencies have a laser-like focus on the issues that impact their agency and that of their constituents. Executive level staff from the single-purpose agencies that participated in the study are very active and hold leadership positions in local and state wide trade associations. Through their involvement with various population-specific advocacy groups, they acquire a deeper understanding of policy issues related to serving persons with intellectual and

developmental disabilities. Information is power, therefore the executives gain political leverage and use their trade association as venues to advocate on behalf of the industry as well as their respective agencies.

At the executive level, multipurpose agencies have no focus on any particular population thereby thwarting its ability to plan and make proactive changes that would accommodate the changing needs of aging consumers who are aging. Instead, in my opinion, executives of multipurpose agencies react to whichever constituent group is in crisis at any given moment that commands their time and attention. The interview findings did not specifically test this phenomenon with multipurpose participant agencies. The participating single-purpose agencies however, reported making accommodations more proactively than their multiservice counterparts. It is important to note that the breath of service areas for the multiservice agencies who participated in this study was no more than two service areas, further limiting any generalizations to the population of multiservice agencies, many of which administer three or more lines of service. Future studies may look at human service providers that operate programs in more than two service areas to ascertain if the level of adaptive responses are directly or indirectly proportional to the number of service areas that an agency operates.

### Practice and Policy Implications

#### *Physical Plant.*

The challenges presented by physical plant issues on the ability of people with intellectual and developmental disabilities to age in place can be significant and cost prohibitive, especially in older multilevel residences. Even when retrofitting a home is possible, it is costly for the

agency and for OPWDD. Many suburban homes for people with intellectual and developmental disabilities are often existing single-family houses built with steps at all entrances, and hallways and doorways that are too narrow for wheelchair users. The challenges in urban areas such as New York City are increased, as property with a footprint large enough to allow the development of single-level living is limited and expensive.

To develop an efficient method of service delivery, the long-term care system must reflect the close interrelationship between housing and health. A customized (person-centered) model of care, matching services and facilities to a person's needs rather than matching a person to an existing facility, avoids the inefficiencies of over-care and under-care. As new single-family homes are developed, builders need to be encouraged to include universal design features. The focus of universal design is to create attractive living spaces that everyone, regardless of age or ability, can use. Universal design features include no-step entry, single-floor living, wide doorways and hallways, reachable controls and switches, and easy-to-use handles and switches.

Placing a person with intellectual and developmental disabilities in a nursing home only because of accessibility issues, even if it is the "option of last resort," is contrary to the Olmstead Decision. In its 1999 ruling in *Olmstead v. L.C.*, the U.S. Supreme Court held that "unnecessary segregation of individuals with disabilities in institutions constitutes discrimination based on disability because it perpetuates unwarranted assumptions that people with disabilities are incapable of participating in community life."

OPWDD and the state should consider leveraging to a greater extent, its underutilized assets from developmental centers that have been or plan be downsized or closed, by creating age-friendly continuing care communities. This state land could be used to develop more barrier-free housing options. Government, voluntary service providers, and private investors could form

partnerships to develop more age-friendly housing options for the generalized older adult population and find creative ways to integrate intellectually and developmentally disabled older persons into their designs. A variety of housing options, along the continuum of care, could be developed such as apartments for independent living, supported housing and supervised housing options. More homes, similar in design to the Buena Vista Homes, discussed in the previous chapter, should be built throughout the state. They can be built, in partnership with community medical centers, as part of continuing care communities, or as part of existing skilled nursing facilities that have been decreasing their census and now have additional capacity. A section or ward of the nursing facility could be designated as “home for medically frail people with developmental disabilities”.

Administrators can play an important advocacy role by bringing the issues and challenges associated with serving the growing number of older adults to its political leadership so that government resources and attention be given to the issue. Building barrier-free homes is not the only important priority. Let us not repeat past mistakes, but instead garner the resources necessary to build in the necessary supports and services that go along with development, so that people with intellectual and developmental disabilities can live the best possible lives they can.

#### *Financial Implications.*

The financial implications of an aging consumer on a provider agency are multifaceted. Although OPWDD provides funding for new construction or for major renovations, the approval process is time-intensive and requires the agency to secure the construction loan. OPWDD will only assume the debt obligation after the construction and all approvals are complete, at which time OPWDD will assume the debt obligation by adding the mortgage/loan payments to the

facility's reimbursement rate over the term of the loan. For provider agencies with a poor credit rating, securing a construction loan may not be possible. OPWDD ties PPAs (Prior Property Approvals) to a per client rate and to the assessed value of the property. Construction costs do not vary very much in New York City; therefore, limiting a PPA to the property's appraised value is bad for organizations with buildings in poor areas that need substantial renovations. In addition, for many major renovations, provider agencies may need to relocate consumers for a few weeks to a year, resulting in additional time, expense, and disruption to consumers.

For consumers who require skilled nursing care and for whom returning to their home is no longer an option, and where the provider agency cannot secure an alternate placement into an appropriate community setting, an agency tends to hold that person's "slot" until the person is successfully discharged from the nursing facility, causing financial hardship on the agency. OPWDD does provide a mechanism for an agency to appeal for reimbursements related to "bed holds" or "vacant beds" only if the agency has a cumulative deficit at year-end and provides a justification, which backs up the appeal. The rate appeal process is labor-intensive for both the agency and for OPWDD. In addition to the practice of holding the person's slot, another common practice, based on the perception that nursing home staff do not know how to care for persons with intellectual and developmental disabilities, is for agencies to assign staff to cover shifts when older consumers are hospitalized or admitted into a nursing home. This coverage is not Medicaid reimbursable. Futuristically, OPWDD should take the lead in educating long-term and short-term care facilities about how best to care for individuals with intellectual and developmental disabilities so that its contracted agencies do not have to subsidize care that Medicaid is already paying for. After all, nursing homes are paid to provide rehabilitation, medical care, room and board and a safe environment. The practice of augmenting nursing home

and hospital staff with agency staff is so commonplace that it has become the norm. Now that agencies are re-evaluating this practice and reducing supplemental staffing, in my recent experience, some nursing homes have made the extra staffing, at the agency's expense, a condition of admission. These nursing homes should be sanctioned so that older persons cannot be denied access to the care they need and are entitled to.

Social workers could play the role of ombudsman, to make sure that clients get admitted into nursing homes and when they are ready to return home they are sent to their prior residence, if able, or to another appropriate and safe environment. Social Workers could also work with community advisory board representatives (CAB) to start a planning committee that would focus not only with advocating for client's rights but also find ways to ease up on the frequency of "bed hold" in instances where it is clear that a resident will not be able to return to a particular residence and holding their bed is wasting scarce resources.

At the encouragement of OPWDD, one of the significant decisions many provider agencies made in the late 1990s through mid 2000s, that have added to the financial challenges of provider organizations serving aging consumers, was the conversion of ICF-DD residences to IRAs and downsizing the number of beds. At the time of the conversions, financing was supposed to be budget neutral. However, with fewer consumers to cover the fixed costs, combined with the additional staff expenditures related to the complex medical needs of aging consumers, conversions of CR's and ICFs to IRAs, especially for smaller provider agencies, are no longer fiscally viable. As funding levels continue to contract due to the country's economic woes, even agencies with larger portfolios will operate in a deficit scenario.

Agency administrators need to educate OPWDD about the financial and programmatic impact that providing quality services at an appropriate level of care has on their agency. OPWDD should pay providers prospectively for the *true cost* of providing services, as long as the agency is achieving desired outcomes. This would reduce the need for rate appeals, saving the service provider and OPWDD, both time and money. Service providers that through efficiencies realize budget surpluses that could then be reinvested in additional supports and services, such as those to support recreational programs for older consumers who choose to retire from day program.

#### *Workforce Implications.*

The growing number of aging consumers has also impacted the agencies' workforce. Study findings indicated a greater need for staff training, supervision and more hands-on support. Caring for medically frail older persons was more physically demanding and necessitated a different skill set for staff such as: proper use of assistive devices and adaptive equipment; how to manage multiple medications, proper use of feeding tubes, suctioning and oxygen equipment; proper transfer and toileting techniques, and how to prevent bed sores. Reported were the increased frequency of job-related injuries and workman's compensation claims, difficulties recruiting staff and a higher turnover rate, all attributed to the increased demands related to serving older consumers.

As consumers who are medically fragile age in place, their needs for nursing services and support increases and creates an even greater demand for a skilled long-term care workforce. Adequate compensation, training, supervision and opportunities for advancement are essential for an agency to recruit and retain workers. Community care saves the government a great deal of money compared to institutional care in a state facility, hospital or nursing home. These savings should be passed along to service providers for them to invest in training programs for

staff at all levels, and to be used for staff incentives such as bonuses or higher pay grades for those who acquire and demonstrate the requisite skills needed to serve older persons with complex needs. OPWDD should take the lead by expanding partnerships with local colleges and state universities to offer programs that would offer professional and graduate-level degrees for direct care, support, clinical, social work, managerial and executive staff. OPWDD could also offer incentives to voluntary agencies that support staff who attend and excel in these professional programs. Everyone benefits from these investments in the workforce; Staff will obtain a new set of skills and a professional or graduate degree, agencies benefit from incentive payments, and the consumers get better care. Social work professionals could also provide staff training on topics such as, how to build relationships, how best communicate the needs of older consumers to external medical providers, and also to assist agency administrators with the development of appropriate outcome measures for the organization, its workforce, and for the older people it serves.

*Programming Implications.*

Older persons with intellectual and developmental disabilities should be able to retire from day programs if that is what they choose to do. There are many financial disincentives for agencies to stop sending consumers to traditional bricks and mortar programs when funding is contingent on attendance, especially if the same agency sponsors both the day program and the person's residential program.

Agencies that honor the wishes of their older consumers and allow them to retire have the added expense of providing added supervision and supports in the residence on weekdays when the consumer would ordinarily have been in a day program. More appropriate programming within

the facility would allow the older consumer to participate in less taxing activities at the time and place that feels comfortable to that older person. OPWDD should allocate resources so that residential staff can be used to cover these daytime shifts required for additional support. At the present time, only staff from a day program can provide day activities in the residence in order for the day program to bill for the service. Given that there are fewer older people in any given home to participate in group activities if they were eligible to do so therefore, using day program staff is not the most efficient model. Using residential staff, augmented by volunteers to accompany staff on community outings would provide greater flexibility and better meet the needs of the agency and of the older people who retired from traditional day programs.

More *flexible* funding that is tied to *outcomes* as opposed to attendance would provide agencies some relief. Flexible funding would also provide a way to test innovative program models designed to keep would keep older consumers engaged and connected with the world as they participate in the activities of their choosing. More flexible programming would allow them to live the best life possible, while at the same time, not bankrupting the agencies that serve them. Agencies would then be able to purchase or provide the services that an older person actually needs as opposed to just having the person get every service available to them, just because they can.

#### *Implications for Medical Care.*

The only obvious distinction between the Buena Vista Homes for the Medically Frail, discussed in the prior chapter, with that of any quality skilled nursing facility, is the number of residents it cares for at any given time. Residential programs similar to the Buena Vista Homes exist in various parts of the state however – there are far too few of them. These homes for the

medically frail are quasi-nursing homes that provide around the clock nursing care and direct supports, in a residential-type setting that are equipped to address highly complex medical needs of its residents. Homes for the medically frail are generally in small residential settings, whereas a nursing homes typically cares for hundreds of people in an institutional type setting. Even so, these small residential alternatives for older persons with intellectual and developmental disabilities with complex medical needs, provide an interim level of services and supports, at a cost that is less than that of a skilled nursing facility. More of these homes should be developed.

Persons with intellectual disabilities and developmental disabilities, especially those with complex medical conditions that require complicated medication regimens and medical treatment, require that their care be managed and monitoring by a well qualified and trained staff. Care coordination and timely communication among residential, nursing, clinical, day program staff, as well as with the older person's primary and specialty care providers are essential to the health and well-being of older adults with intellectual and developmental disabilities. These are essential components of environments for older people in order to facilitate their successful aging in place.

An essential component of health care reform legislations is care coordination and employing the use of technology to better communicate and coordinate a person's medical care. Along this vain, OPWDD should expedite its plan to develop an electronic health record, to expand the use of telemedicine and allow as an added support, the use of aging-specific technology developed to monitor vulnerable individuals. Another important outcome of health care reform is the reduction of costly emergency room visits. Service providers throughout New York that work with people with developmental disabilities are the worst offenders in terms of their overreliance

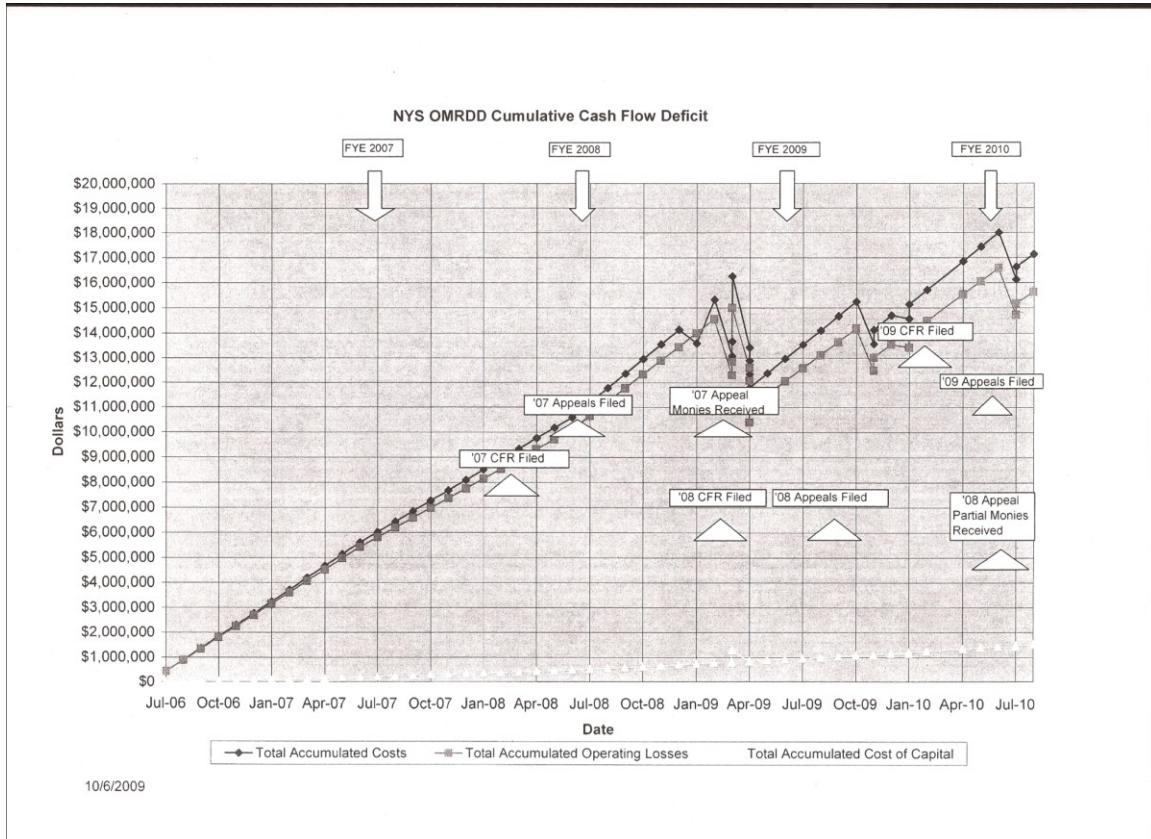
on emergency rooms for times when a less acute level of medical care would suffice. As mentioned earlier in this report, service providers often send their consumers to the emergency room, in order to minimize their liability against not providing the necessary treatment in the event of a true medical emergency. If the provider fails to provide timely medical attention to a consumer, they receive a citation from OPWDD that could put their agency into immediate jeopardy. If health care reform initiatives are going to work with this special needs population, regulatory reform on the part of OPWDD will have to precede any changes in the way health care is managed. Service providers and OPWDD will need to develop a higher risk tolerance for potential exposure to abuse and neglect. If providers continue to a citation each time an older consumer gets a scratch on them or breaks a fingernail, then providers will never be able to achieve the outcomes and efficiencies that are grounded in health care reform and implied within OPWDD's People First Waiver. This is not to say that OPWDD needs to abandon its role in providing regulatory oversight. Quite the contrary. Recognizing the inherent risks in caring for vulnerable individuals, OPWDD should ease regulations to the extent that service providers can reasonably provide quality care without the preoccupation with regulatory compliance. The more recent knee jerk reactions of OPWDD over every negative news story regarding instances of abuse and neglect on behalf of workers in state operated facilities, has resulted in even more regulations. OPWDD cannot continue to add additional regulatory burdens onto agencies at the same time that it attempts to transform the service system to one that is more *person-centered* and *flexible* and has the principals of individualized supports and managed care as its core components. Innovation and creative reinvention of the service delivery system for intellectually and developmentally disabled New Yorkers can only be accomplished by incorporating genuine flexibility in its design, and more importantly - in its implementation.

*Suggestions for Future Research.*

Future studies which broaden the scope of this study by including the perspectives of direct care staff, consumers, advocates, parents, and OPWDD leadership, with the purpose of gaining a deeper understanding of what these stakeholders believe is the best way to facilitate the successful aging place of older consumers with intellectual and developmental disabilities.

If approved by CMS, the initiatives related to the People First Waiver, will create many opportunities for future program and process evaluations that focus on rate reform, quality outcome measures, case studies, and the efficacy of the transition from a fee-for-service model to a managed long-term care model of service delivery. Future studies should illuminate the extent to which regulatory relief, granted under the waiver authority, has ameliorated many of the challenges identified in this study.

Appendix A Cumulative Cash Flow Deficits



Cumulative Cash Flow Deficit

## Appendix B IRB Approval Letters Research with Human Subjects

**HUNTER**

The City University of New York

INSTITUTIONAL REVIEW BOARD (IRB)  
695 Park Avenue, Room E12303  
New York, NY 10021-5085  
Telephone: (212) 650-3053  
Fax: (212) 650-3055  
[www.hunter.cuny.edu/irb](http://www.hunter.cuny.edu/irb)

June 24, 2010

Donna Corrado  
Michael Smith  
Social Welfare

**RE: 10-06-197-4471 "The Graying of Older Adults with Intellectual Disabilities:  
Organizational Efforts of Community Service Providers in Adapting Facilities and  
Programming to Meet the Needs of Older Adults"**

Dear Ms. Corrado:

The Hunter Amethyst IRB: IRB00004471 has approved the above study involving humans as research subjects. This study was Approved - Expedited Category: 7 - based on 45CFR46.

**IRB Number: 10-06-197-4471** This number is a Hunter Amethyst IRB: IRB00004471 number that should be used on all consent forms and correspondence.

**Approval Date: June 22, 2010**  
**Expiration Date: June 21, 2011**

THIS APPROVAL IS FOR A PERIOD OF ONE-YEAR OR LESS. YOU SHOULD RECEIVE A COURTESY RENEWAL NOTICE BEFORE THE EXPIRATION OF THIS PROJECT'S APPROVAL. HOWEVER, IT IS YOUR RESPONSIBILITY TO INSURE THAT AN APPLICATION FOR CONTINUING REVIEW APPROVAL HAS BEEN SUBMITTED BEFORE THE EXPIRATION DATE NOTED ABOVE. IF YOU DO NOT RECEIVE APPROVAL BEFORE THE EXPIRATION DATE, ALL STUDY ACTIVITIES MUST STOP UNTIL YOU RECEIVE A NEW APPROVAL LETTER. THERE WILL BE NO EXCEPTIONS. IN ADDITION, YOU ARE REQUIRED TO SUBMIT A FINAL REPORT OF FINDINGS AT THE COMPLETION OF THE PROJECT.

**Consent Form:** All research subjects must use the approved and stamped consent form. You are responsible for maintaining signed consent forms for each research subject for a period of at least three years after study completion.

**Mandatory Reporting to the IRB:** The principal investigator must report, within five business days, any serious problem, adverse effect, or outcome that occurs with frequency or degree of severity greater than that anticipated. In addition, the principal investigator must report any event or series of events that prompt the temporary or permanent suspension of a research project involving human subjects or any deviations

**HUNTER**

The City University of New York

INSTITUTIONAL REVIEW BOARD (IRB)

695 Park Avenue, Room E1204

New York, NY 10065

Telephone: (212) 650-3053

Fax: (212) 650-3055

www.hunter.cuny.edu/irb

June 1, 2011

Ms. Donna Corrado

**RE: 10-06-197-4471 The Graying of Older Adults with Intellectual Disabilities:  
Organizational Efforts of Community Service Providers in Adapting Facilities and  
Programming to Meet the Needs of Older Adults**

Dear Ms. Corrado:

The Hunter Amethyst IRB: IRB00004471 has approved the above study involving humans as research subjects. This study was Approved - Expedited Category: 8 - based on 45CFR46.

**IRB Number:** 10-06-197-4471 This number is a Hunter Amethyst IRB: IRB00004471 number that should be used on all consent forms and correspondence.

**Approval Date:** May 26, 2011

**Expiration Date:** May 25, 2012

THIS APPROVAL IS FOR A PERIOD OF ONE-YEAR OR LESS. YOU SHOULD RECEIVE A COURTESY RENEWAL NOTICE BEFORE THE EXPIRATION OF THIS PROJECT'S APPROVAL. HOWEVER, IT IS YOUR RESPONSIBILITY TO INSURE THAT AN APPLICATION FOR CONTINUING REVIEW APPROVAL HAS BEEN SUBMITTED BEFORE THE EXPIRATION DATE NOTED ABOVE. IF YOU DO NOT RECEIVE APPROVAL BEFORE THE EXPIRATION DATE, ALL STUDY ACTIVITIES MUST STOP UNTIL YOU RECEIVE A NEW APPROVAL LETTER. THERE WILL BE NO EXCEPTIONS. IN ADDITION, YOU ARE REQUIRED TO SUBMIT A FINAL REPORT OF FINDINGS AT THE COMPLETION OF THE PROJECT.

**Consent Form:** No consent forms are attached because no more subjects will be recruited and activities are limited to data analysis/publication. If you are using a consent form, all research subjects must use the approved and stamped consent form. You are responsible for maintaining signed consent forms for each research subject for a period of at least three years after study completion.



## Human Research Protections Program

Hunter College (CUNY) HRPP Office

DATE: June 21, 2012

TO: Donna Corrado, PhD Candidate  
FROM: Hunter College (CUNY) HRPP Office

PROJECT TITLE: [297480-2] The Graying of Older Adults with Intellectual Disabilities:  
Organizational Efforts of Community Service Providers in Adapting Facilities  
and Programming to Meet the Needs of Older Adults

SUBMISSION TYPE: Continuing Review/Progress Report

ACTION: APPROVED  
APPROVAL DATE: June 21, 2012  
EXPIRATION DATE: June 20, 2013  
RISK LEVEL: Minimal Risk

REVIEW TYPE: Expedited Review  
REVIEW CATEGORY: Expedited review category # 8

Thank you for your submission of Continuing Review/Progress Report materials for this project. The University Integrated IRB has APPROVED your research. This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

Please note that any modifications/changes to the approved materials must be **approved by this IRB prior to implementation**. Please use the appropriate modification submission form for this request.

All **UNANTICIPATED PROBLEMS (UPS)** involving risks to subjects or others, **NON-COMPLIANCE** issues, and **SUBJECT COMPLAINTS** must be reported promptly to this office. All sponsor reporting requirements must also be followed. Please use the appropriate submission form for this report.

This research **must receive continuing review and final IRB approval** before the expiration date of June 20, 2013. Your documentation for continuing review must be received with sufficient time for the IRB to conduct its review and obtain final IRB approval by that expiration date. Please use the appropriate continuation submission forms for this procedure. PLEASE NOTE: The regulations do **not** allow for any grace period or extension of approvals.

If you have any questions, please contact the Hunter College HRPP office at (212) 650-3053 or [hrpp@hunter.cuny.edu](mailto:hrpp@hunter.cuny.edu). Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within the City University of New York's records.

## Appendix C Human Research Curriculum Completion Reports

**CITI (Collaborative Institutional Training Initiative)****Human Research Curriculum Completion Report  
Printed on 09/16/2012****Learner:** Donna M. Corrado (user name: dcorrado)**Institution:** City University of New York (CUNY)**Contact Information:** 85 Forestdale Road

Rockville Center, NY 11570 USA

Department: School of Social Welfare

Phone: (718) 722-6123

E-mail: [corradowonna@gmail.com](mailto:corradowonna@gmail.com)**HSR for HRPP Staff:** Regardless of whether the research is Social and Behavioral, or Biomedical.**Stage 2. Refresher Course Passed on 12/25/11 (Ref # 6866959)**

<b>Required Modules</b>	<b>Date Completed</b>	<b>Score</b>
SBR 101 REFRESHER MODULE 3 - Risk, Informed Consent, and Privacy and Confidentiality	12/25/11	5/5 (100%)
<b>Elective Modules</b>	<b>Date Completed</b>	<b>Score</b>
How to Complete the CITI Refresher Course and Receive the Completion Report	12/25/11	No quiz

**For this Completion Report to be valid, the learner listed above must be affiliated with a CITI participating institution. Falsified information and unauthorized use of the CITI course site is unethical, and may be considered scientific misconduct by your institution.**

Paul Braunschweiger, Ph.D.  
Professor, University of Miami  
Director Office of Research Education  
CITI Course Coordinator

**Human Research Curriculum Completion Report****Printed on 1/21/2013****Learner:** Donna M. Corrado (username: dcorrado)**Institution:** City University of New York (CUNY)**Contact** 85 Forestdale Road**Information** Rockville Center, NY 11570 USA

Department: School of social work

Phone: 718-722-6123

Email: corradodonna@gmail.com

**HSR for HRPP Staff:** Regardless of whether the research is Social and Behavioral, or Biomedical.**Stage 1. Basic Course Passed on 01/11/09 (Ref # 2401570)**

<b>Required Modules</b>	<b>Date Completed</b>	<b>Score</b>
The City University of New York (CUNY) Module	01/04/09	no quiz
History and Ethical Principles - SBR	01/06/09	5/5 (100%)
Defining Research with Human Subjects - SBR	01/07/09	5/5 (100%)
The Regulations and The Social and Behavioral Sciences - SBR	01/08/09	5/5 (100%)
Assessing Risk in Social and Behavioral Sciences - SBR	01/08/09	5/5 (100%)
Informed Consent - SBR	01/11/09	4/4 (100%)
Privacy and Confidentiality - SBR	01/11/09	4/4 (100%)
Records-Based Research	01/11/09	2/2 (100%)
Research with Children - SBR	01/11/09	5/5 (100%)
Research in Public Elementary and Secondary Schools - SBR	01/11/09	4/4 (100%)
Internet Research - SBR	01/11/09	5/5 (100%)

**For this Completion Report to be valid, the learner listed above must be affiliated with a CITI participating institution. Falsified information and unauthorized use of the CITI course site is unethical, and may be considered scientific misconduct by your institution.**

Paul Braunschweiger Ph.D.  
 Professor, University of Miami  
 Director Office of Research Education  
 CITI Course Coordinator

## Appendix D

### Letter of Introduction

March 21, 2010

Dear Executive Director,

My name is Donna M. Corrado and you may know me in my role as the Chief Operating Officer of Catholic Charities Neighborhood Services, Inc., of Brooklyn and Queens. I am also a Doctoral Candidate at CUNY Graduate and University Center, Hunter College School of Social Welfare, and it is in this capacity that I am reaching out to you today.

Under the advisement of Professor Michael J. Smith, I will be conducting a study as part of my doctoral research that will examine the adaptive responses of organizations that serve individuals with intellectual disabilities who are aging. Catholic Charities supports this study in so far as the challenges inherent in its serving an older adult population are being experienced every day and at a variety of levels. The study will add to the practice knowledge in the fields of disability and aging services, and as a result, Catholic Charities also endorses the topic as one of interest and worthy of further exploration.

Your organization is one of a diverse sample of organizations in New York State that meet the study criteria by offering residential opportunities to older adults with intellectual disabilities, including those who are over the age of fifty. I am writing to offer your agency the opportunity to participate in this important study. Participation in the study will involve interviews with key personnel in addition to examining management reports, annual reports, strategic plans and financial data. The study will be conducted according to the standards set by the CUNY Graduate Center's Institutional Review Board and, as such, will maintain the highest level of confidentiality of study participants, as well as the anonymity of all participating organizations.

I am including a self-addressed letter, which can be reproduced on your agency letterhead attesting to the willingness of your agency to participate in the study. Please sign and return this letter in the envelope provided, at your earliest convenience. Once the study has been approved by the CUNY Graduate Center's Institutional Review Board, I will contact you to request from you the name and contact information of the person from your agency with whom I can work with to coordinate interviews and collect relevant data.

If you have questions regarding the study, please do not hesitate to call me at 718-640-5035 or email me at [Dcorrado@ccbq.org](mailto:Dcorrado@ccbq.org) or [corradoonna@gmail.com](mailto:corradoonna@gmail.com).

Your participation in the study is eagerly anticipated and greatly appreciated.

Best regards,

Donna M. Corrado, LCSW  
PhD Candidate

## Appendix E Letter of Intent

Donna M. Corrado, LCSW  
215 Adams Street #8H  
Brooklyn, NY 11201

Dear Ms. Corrado,

I am in receipt of your invitation to participate in the study of organizations serving older adults with intellectual disabilities. On behalf of X Agency, I accept this invitation to participate in the study and I understand that participation in the study is voluntary and that the name and identity of the agency, staff and participants will remain confidential.

I look forward to working with you on completing this important study and I will contact you if I have any questions or need further information regarding the study.

Signature – Agency Executive

## Appendix F



Hunter College of C.U.N.Y.  
Institutional Review Board (IRB)  
PROTOCOL #: 10-06-197-4471  
APPROVED:  
FROM: 6/22/10 TO: 6/21/11

Informed Consent Form

The Graying of Adults with Intellectual Disabilities: Organizational Efforts of Community Service Providers in Adapting Facilities and Programming to Meet the Needs of Older Adults is a research study will be carried out by Donna Corrado, LCSW under the supervision of Professor Michael J. Smith, faculty for Hunter College School of Social Work.

The proposed qualitative study will explore the ways in which community based agencies serving persons with intellectual disabilities have adapted their services and facilities to accommodate an ever growing cohort of older adults with intellectual disabilities. The focus of the study is to examine how each of these organizations promotes successful aging through evaluation of the organizational adaptations made according to the following themes:

- physical plant issues
- funding and resource allocation issues
- workforce issues
- medical and health issues
- specialized programming

The results of the study will be incorporated into a completed dissertation as required for completion of the PhD program. Please feel free to ask any questions now or at any time during the study.

Participation in the study is voluntary and you may withdraw from study at any point during the process or up to three months after your individual interview. The names of research participants as well as participating organizations will be kept confidential to the fullest extent of the law. No one in your agency will be told if you participate, decline to participate or if you withdraw from the study at any point and for any reason.

Participation involves a personal interview, preferably face to face, of one to two hours in duration. The meeting will take place at my office in downtown Brooklyn or at a more convenient location of your choosing. The interview will be audio-recorded and later transcribed verbatim. All transcripts will be treated as confidential material. Once the recording has been transcribed the tapes will be destroyed. All tapes and transcripts will be stored by in a locked cabinet in my home office where only I have access to the cabinet. All confidential materials will be destroyed after three years of completion of dissertation. You may be quoted in the final dissertation write up however no name or identifying information will accompany the quotes. If requested, you may receive a final summary of the study findings.

## Appendix G Interview Guide and Probes

1. What impact has the aging of consumers had on your organization?

*Probe:* What are some of the challenges that you have encountered in recent years as it relates to your consumers as they age-in-place?

*Probe:* Is the aging of consumers a concern for your agency?

---

2. Are there physical plant issues that have become barriers for your older consumers to successfully age-in-place?

*Probe:* Has your agency needed to make environmental modifications to your residences to accommodate older consumers?

*Probe:* Have you developed new facilities or retrofitted existing structures so that older consumers may age-in-place?

---

3. How have these barriers been overcome?

*Probe:* What types of alterations to residential and program facilities have been made in recent years?

*Probe:* Has your agency taken proactive measures to accommodate the needs of older adults?

---

4. Has your agency developed specific programming for older adults?

*Probe:* How are issues of retirement negotiated for your older consumers?

*Probe:* How are issues of community inclusion and socialization addressed in relation to older consumers?

- 
5. Describe how your agency's programs for older consumers with intellectual disabilities differ from that of programming for general older adult population?

*Probe:* Describe a typical day in the life of an older resident of one of your group homes.

*Probe:* How would you describe an ideal program for older consumers?

---

6. How has your agency come to respond to the growing number of consumers who are aging?

*Probe:* In what way has your board of directors been informed and involved with how your agency responds, if any, to the growing number of older consumers?

*Probe:* Does your agency's strategic plan or annual plan address the issue of older consumers?

---

7. How has your agency addressed the needs of medically frail older adults?

*Probe:* How do your aging consumers access health-related services?

*Probe:* Under what circumstances do you admit older consumers to nursing homes, and when are older consumers discharged back to residence?

---

8. What type of impact has the aging of consumers had on your workforce?

*Probe:* What type of specialized training have they had in relation to caring for older consumers with intellectual disabilities?

*Probe:* Does your agency provide any incentives to direct care professionals to work with older consumers?

9. How have the additional costs associated with caring for older consumers affected your agency?

*Probe:* Has your agency requested rate adjustments or submitted rate appeals to OPWDD to recoup funding deficits related to caring for older consumers?

*Probe:* In what ways has your agency subsidized or diversified funding as a response to greater financial pressures related to caring for older consumers?

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10. How has your agency made decisions around allocating resources to address the needs of older consumers?

*Probe:* Has the agency established as a priority to address the issues related to the aging of its consumers with intellectual disabilities?

*Probe:* Does your agency strategic plan, marketing materials, annual reports specifically mention the issues relating to the growing number of consumers served by the agency who are aging?

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