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CHANGE AND INERTIA IN THE NEW YORK STATE MEDICAID PERSONAL CARE SERVICES
PROGRAM:
AN INSTITUTIONAL CASE STUDY

by
Toby Adelman

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

Nursing

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

UMI Number: 3289345

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ACKNOWLEDGMENTS

I appreciate the New York State and City officials, directors of provider agencies, union officials, and consumer advocates who participated in the case study. My deepest respect for the work you do and your willingness to take time out to share your views with me.

I am indebted to many people for seeing me through to this juncture of the doctoral program. I wish to thank the UCSF School of Nursing Office of Student Affairs. Jeff Kilmer and the entire staff assisted me in navigating my return to graduate school and provided exceptional support throughout the process. I also thank Dorrie Fontaine, Zina Mirsky, and Nancy Stotts, for providing guidance to my cohort of UCSF/ Betty Irene Moore Fellows. While privileged to be amongst this bright and motivated group, I absorbed with deep appreciation the words of encouragement that you, as faculty, provided. Likewise, I wish to thank Jeanie Kayser-Jones for opening the door and welcoming me to the UCSF John A. Hartford Center for Geriatric Nursing Excellence functions where I had the joyful opportunity of meeting many of the best leaders in nursing today. In addition, the Social and Behavioral Department faculty, staff, and students, provided a home away from home for three years and became like family to me on my journey. I am grateful to you all for providing such a warm and welcoming space to grow. And thank you, Theo, for so generously sharing your cubicle space.

I thank my qualifying examination and doctoral committees for your guidance and support. My first understanding of how exciting health policy research could be was witnessing you, Bob Newcomer, Nancy Miller, Martin Kitchener, and Charlene Harrington, discuss between yourselves the papers I had brought before you for my qualifying examination. Your passion for the work and your willingness to allow me into your worlds to learn from you are precious gifts that I will treasure forever. To be able to know you, and to be made to feel a welcome part of the UCSF Personal Assistance Services (PAS) Center research team with you, has been one of the best experiences a return to graduate study could provide. Thank you each for your generosity of spirit and knowledge.

A warm thank you to my siblings, and your spouses and children, for all the inspiration you give to me. I love having the vantage point that I do to watch you all dream big and follow through in your creations. And to you, Mom and Dad, for always being there. Words cannot express my appreciation for all that you are and have done for me. I am delighted, so very delighted, that I can dedicate this humble work to you. I thank you for teaching me, by example, how to do the right thing. I love you for that and for so much more. May all of my actions be for a blessing and honor that teaching.

Special thanks are in order for my friends, many who have known me through most of the chapters of my life and are instrumental in my writing this one. Thank you Elise, Chas, Russ, David, Harry, Mort, Stan, Joseph, MK, Mordechai, Cynthia, and Beth. I am grateful to each of you. I can also testify to it “taking a village” to raise a child, especially when pursuing graduate studies. In addition to my family and friends, I thank the many nameless (too many to name) members of our village who allowed me to return to school and to do so knowing that my daughter, Shy, was in good hands. I thank you Mary Connell, Chief of that village,

and all. And to you, Shy, thank you for encouraging me to go for it and for so generously giving of yourself to make it happen. UCSF may not hand out honorary degrees, my dear, but I do and lovingly share this one with you. You have earned it.

Albert Einstein noted that, “not everything that can be counted counts, and not everything that counts can be counted”. My deepest, immeasurable gratitude goes to my academic advisor, Charlene Harrington. I understand more deeply now, because of you, that teaching is demonstrating. I have watched, and learned, and can only hope to model and pass on what I have so generously been given. In my relationship as a student with you I experience trust, honesty, tolerance, gentleness, joy, generosity, open mindedness, and a never-ending supply of patience, as you demonstrate what teaching is, Charlene. You live these values as part of your work ethic and I, one of your many grateful students, am indebted to you for sharing them with me. Thank you for everything. ~ Toby

ABSTRACT

CHANGE AND INERTIA IN THE NEW YORK STATE MEDICAID PERSONAL
CARE SERVICES PROGRAM: AN INSTITUTIONAL CASE STUDY

Toby Adelman RN, PhD c.

University of California, San Francisco, 2007

This study draws from institutional theory to analyze how the competing logics (belief systems) of stakeholders have influenced patterns of change and inertia in the development of the New York State Medicaid Personal Care Services Program. A case study methodology was used to conduct face-to-face and telephone interviews with four key stakeholder groups: state and city officials; agencies providing personal care services; labor unions; and consumer advocacy organizations. Interview data, documents, and statistical trend data were collected on the program from 1999-2005. Results of the inquiry confirmed the importance of competing logics in a number of ways. First, the development of the program was strongly influenced by founding (imprinted) conditions, especially the early unionization of workers that resulted in relatively generous wages and a stable, agency-based program. Second, public support and pressure, from both individuals and collective disability groups, to expand a consumer-directed delivery model of personal care services is challenging the status quo. However, while the optional consumer-directed model of care is expanding slowly, there is considerable resistance from stakeholders whose logics legitimate agency-based models. Expressed logics elaborated by study participants help explain how belief systems have influenced patterns of change and inertia in the program, especially concerning the growing demands for consumer-direction.

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CHAPTER ONE

INTRODUCTION

Although the majority of long-term care (LTC) in the United States (US) is still provided informally, typically by unpaid family and friends (LaPlante, Harrington and Kang, 2002), policy-makers face mounting pressures to expand access to formal, paid, home and community-based services (HCBS). The programs are designed to enable those who qualify for and require such services to live as independently as possible rather than in institutions such as nursing homes (Kitchener, Ng, Willmott, & Harrington, 2005).

Formal, paid personal care services (PCS) may include a range of human assistance provided to persons with disabilities and chronic conditions of all ages, enabling them to accomplish tasks they could normally do for themselves if they did not have a need for such services due to chronic illness or disability (LeBlanc, Tonner, & Harrington, 2001). PCS typically involve hands-on assistance with activities of daily living (ADLs) such as eating, bathing, bladder and bowel requirements, and dressing, and may also include instrumental activities of daily living (IADLs) such as taking medications and shopping for groceries (LeBlanc et al., 2001).

In the US, formal personal care is paid for by a combination of private sources, including out of pocket expenditure, limited indemnity, employer-based insurance markets and by government programs (Kitchener, Willmott, & Harrington, 2004). While Medicaid funds the majority of formal PCS, other sources fund limited amounts of HCBS through personal resources and private long-term care insurance, Medicare and other federal agencies, and state and local governments provided through: the Older Americans

Act (OAA, 2006) Title III, the U.S. Department of Veterans Affairs' Housebound and Aid and Attendance Allowance Program (2006); the Medicare Home Health Benefit (2006); and, Title XX Social Security Block Grants (2006) (Kitchener, Willmott, & Harrington, 2004).

States primarily provide PCS to eligible Medicaid beneficiaries through a variety of state plan and waiver programs. Waiver programs allow states flexibility in designing programs that meet the needs of beneficiaries and are used to control Medicaid spending. These include 1115 demonstration, 1915(a) and 1915(b) managed care and freedom of choice, and 1915(c) home and community-based services (HCBS) waiver programs (Kitchener, et al., 2004; Levinson, 2006). In contrast, the Medicaid state plan optional benefit for PCS must be provided to all categorically needy on a statewide basis. Thirty-states offer PCS under the state plan optional benefit program (Kitchener, Ng, Carrillo, Miller, and Harrington, 2007).

STATEMENT OF THE PROBLEM

Previous studies of HCBS have given limited attention to PCS and, while it is known that many elderly and disabled persons rely on formal PCS to remain independent (Stone, 2001), limited information is available about the largest Medicaid program that provides it, the optional State Plan Personal Care Services benefit program. This program has become a major funding mechanism for PCS used by the elderly and by younger, physically disabled persons living in the community (LeBlanc, Tonner, & Harrington, 2001), although this varies from state-to-state (Kitchener, Carrillo, & Harrington, 2004; Kitchener, Ng, Carrillo, Miller, and Harrington, 2007; Kitchener, Ng, Miller, & Harrington, 2005).

There is a growing interest in state home and community based service programs. The Center for Medicare and Medicaid Services (CMS) examined a number of these HCBS programs and created a repository of case studies (*Promising Practices*, 2006) to promulgate innovative ideas on various state programs that might serve as exemplars to other states and key stakeholders. *Promising Practices* is a collection of 79 case studies to-date that, although not focused exclusively on PCS, bring into wide view the salient features of HCBS in many different states. The CMS case studies represent better practices and offer a perspective on a variety of state programs.

Researchers at the UCSF Center for Personal Assistance Services (2007) have specifically focused on state PCS programs to understand factors that facilitate, or create barriers to, the development of better practices in programs offering PCS through the optional state benefit (Kitchener, Grossman, Ng, Willmott, & Harrington, 2005; Kitchener et al., 2005; Kitchener, Willmott, & Harrington, 2006; Kitchener, Ng, Willmott, & Harrington, 2006). Four Center case studies are focused on better practices in Arkansas, New Mexico, Texas, and Washington, which are posted on the PCS Center website (PCS Center, 2006). One goal of the PCS Center case studies is to examine how the programs are administered and managed and how they relate to other HCBS programs in the states studied. Significantly, none of the studies has examined PCS in New York State. The aim of the study is to fill this gap.

PURPOSE OF THE STUDY

Pressures are building on states to expand services and to move away from the traditional agency model of LTC and toward independent care providers, consumer-directed care, funding, and counseling (Kitchener, Ng, Willmott, & Harrington, 2005).

As NY begins changing its PCS program to offer some of these consumer directed services, it can be seen as a paradigm for better understanding the social, political, and economic forces that drive the PCS model of care. It will be useful to examine the developments taking place in NY State (NYS) as stakeholders seek to change the PCS program to conform to new sets of demands that are being made on it.

New York (NY) is a large northeastern state whose long history of providing HCBS can provide a useful baseline comparison standard for the experience of states where case studies have already been completed. The NY Medicaid PCS program has been in operation for over 25 years and is one of the largest of any of the states. Table 1 shows that, compared to other states, NY ranks first in total Medicaid spending in the US, as well as in state LTC spending per capita in 2002 (Gibson, Gregory, Houser, & Fox-Grange, 2004). Moreover, NY ranks first in expenditures per capita for LTC, HCBS, and for PCS. Demographically, as of 2001, it ranked 5th in participants per 1000 population, after Arkansas, Missouri, California, and Michigan (Gibson et al., 2004).

Table 1. NY State Medicaid and LTC State Expenditures & Rank as Compared to the US in 2002

	State	Rank	US
Total Medicaid Spending (in millions)	\$38,480	1	\$259,565
LTC Spending per Capita	\$815	1	\$288
Nursing Facility Spending per Capita	\$371	1	\$154
HCBS Spending per Capita	\$317	1	\$95.
Personal Care Spending per Capita	\$144	1	\$22

Gibson, Gregory, Houser, & Fox-Grange (2004). Across the States: Profiles of Long-Term Care: NY.

The NY PCS program has several other noteworthy features that justify closer examination. It is primarily an agency-based program with a smaller division offering consumer-based care, in contrast to programs in other states that use independent care providers in addition to agency-based care. The NY program is contracted primarily by means of bids to private PCS provider agencies rather than to independent care providers,

which are widely used in western states (Kitchener, Ng, & Harrington, 2007). In NY, mainly licensed home health and personal care agencies qualify as service providers for the NYS PCS program, however, since 1995, a small but growing number of beneficiaries receive services through a consumer-directed personal assistance program (CDPAP) which does allow independent providers to those participants capable of self-direction. Another significant difference in NY is widespread unionization of the workforce. In NY City (NYC), the contract agency for PCS has been unionized since the 1960s. Currently, the Service Employees International Union 1199 (SEIU, 2006) has over 70,000 members who are home care attendants, house keepers, and home health aides, predominantly in NYC. SEIU 1199 (2006) reports its homecare division is its largest and single fastest growing division.

SPECIFIC AIMS

This study had three specific aims:

Aim 1:

To describe the NYS PCS program in terms of its governance, organization, and management structure, including the extent of its consolidation, integration, and decentralization.

Aim 2:

To examine trends in the NYS PCS program, specifically in the participants and expenditures, from 1999-2005.

Aim 3:

To examine how competing logics of key stakeholders are influencing change and inertia in the NYS PCS program.

The themes underlying the study are that:

- The NYS PCS program is decentralized and is not well integrated with other LTC programs in the state.

- The level of service and care provided by the NYS PCS program and its sustainability has depended on a broad coalition of stakeholder groups and public support for the program.
- The design of the NYS agency-based PCS program primarily stems from the early unionization of PCS workers and the traditional support for unions in NYC that has resulted in generous worker wages and benefits, and a stable program.
- The pressures from key stakeholders, both individuals and collective disability groups, to expand consumer-directed delivery of PCS in NY have challenged the status quo of the NYS PCS's, primarily, agency-based program, leading to structural and management changes and the expansion of the optional consumer-directed alternative delivery model.

This study describes and analyzes the NYS PCS program to understand how it has developed and evolved. Four data sources have been used: 1) documentary research; 2) secondary data analysis; 3) interviews with state and local officials, and 4) interviews with representatives of other key stakeholder groups. The qualitative and quantitative data used were combined to address the three specific aims outlined above.

SIGNIFICANCE OF THE STUDY

This case study focusing on NY contributes its findings to a larger, multi-state study led by the research team at the UCSF Center for Personal Assistance Services (PAS, 2007). Trends in the NY PCS program are of interest to policy makers and stakeholders in other states because NY is a dominant force in personal care policy and delivery in the US, and because of its large population, geographic area and its resulting political influence. Policy makers and stakeholder groups, including those responsible for the optional PCS in other states, are also interested in how NY has been able to maintain its level of commitment for funding the PCS program and its participants despite a current fiscal climate marked by a scaling back of social services. Finally, this case study identifies changes over time in the NY PCS program as competing stakeholder desires

and expectations evolve in response to shifts in the contemporary personal care environment in the state.

CHAPTER TWO

BACKGROUND

The author's interest in HCBS derives from her doctoral studies with the University of California, San Francisco's (UCSF) Center for Personal Assistance Services (PAS, 2007) research team. Funded by the National Institute on Disability and Rehabilitation Research, the PAS Center provides research, training, dissemination, and technical assistance on issues of PCS in the United States. Also, prior to entering doctoral study in the area of health policy and health services research, the author was responsible for supervising a state and federal Medicaid 1915(c) waiver program that provides formal personal care to adults for the city and county of San Francisco, California. The experience inspired a deeper interest in HCBS policy research, specifically the delivery of formal personal care in the home and community setting.

The delivery of personal care in the home and community setting is a national focus of concern to many stakeholder groups. The pressure to expand HCBS increased significantly in 1999 when the Supreme Court ruled in the *Olmstead* case (Olmstead, 1999) that unjustified institutionalization of persons on public programs constitutes discrimination in violation of the 1990 Americans with Disabilities Act (ADA) (Kitchener, Ng, & Harrington, 2005). As documented on the PCS Center website (<http://www.pascenter.org/olmstead/>), post-Olmstead consumer litigation against certain states has provided further impetus for change and indicates a strong desire by many people to remain in, or return to, the community setting to receive required formal PCS.

Title XIX of the Social Security Act of 1965 established the Medicaid program.

Among other services, states were mandated to provide Medicaid nursing facility services and home health services for those individuals who would otherwise be in institutions.

Three principal Medicaid HCBS programs offer PCS in the United States: 1) the optional state PCS programs; 2) 1915(c) HCBS waivers; and the 3) Home Health programs.

Medicaid HCBS Programs

Medicaid has allowed states, and LTC administrators, the flexibility to tailor benefits and scope of coverage to local needs as well as serve as “laboratories for innovation” (Rowland & Tallon, 2004). This flexibility has supported the development of HCBS over the last twenty years. Medicaid spending for LTC more than doubled in a decade (fiscal 1987-1997), rising from \$21.1 billion in fiscal 1987 to \$56.1 billion in fiscal 1997 (Coleman, 1999). This confirms expenditure reports that showed states allocating an increasing share of that spending to HCBS.

In fiscal year 2004, spending for community-based LTC services rose to 36 percent of all Medicaid LTC costs, with 64 percent spent on institutional services. This is a distribution that continues to change by one to three percentage points each year, as Medicaid programs continue to invest more resources in alternatives to institutional services (Burwell, Sredl, & Eiken, 2005).

The only two mandated Medicaid LTC benefits are institutional care and home health services for those participants eligible for institutional care (Harrington, Laplante, Newcomer, Bedney, Shostak, Summers, Weinberg, & Basnett, 1998). Medicaid regulations also allow states to use combinations of three programs to provide home and community-based services either directly, or through a variety of contractual agreements:

the Optional State-Plan PCS Program, 1915(c) waivers, and mandatory home health (Kitchener, Ng, Miller, & Harrington, 2005).

Medicaid State Plan Personal Care Services Program

Since 1975, states have had the option of offering PCS as a Medicaid benefit (CMS, 2006). States have considerable discretion in defining PCS, but these programs typically involve the provision of non-medical assistance with ADLs such as bathing and eating for participants with disabilities and chronic conditions. States vary in the amount and scope of services they provide. For example, only some states provide PCS outside the participant's residence (Kitchener, Ng, & Harrington, 2005). Unlike waivers, when the PCS program is offered as a state plan benefit, it must be made available statewide to all categorically eligible persons (CMS, 2006).

By 1979, only 10 states had active PCS programs (Doty, Kasper, & Litvak, 1996). Since then, the optional state PCS program has become the largest publicly-funded mechanism for formal community-based personal care used by the elderly and by younger persons with disabilities (Kitchener, Carrillo, & Harrington, 2006). Of the Medicaid approaches offering personal care, the PCS benefit is offered by the fewest states, 32 to date (Kitchener, Ng, Miller, & Harrington, 2005).

If personal care services are covered as a state plan benefit, the services must be made available to all individuals who are eligible for the benefit and who do not live in institutions. Therefore, there cannot be a cap on the number of people who receive this benefit, and waiting lists cannot be kept for services. States do use other methods to control utilization, however (Kitchener et al, 2005). For example, there may be limits on the amount or cost of services provided.

Personal care services are vitally important to many people with disabilities who wish to remain in the community but need assistance with everyday activities. All states use a variety of sources of public funding to finance PCS, but the Medicaid program is by far the largest source of funding. With the trend toward providing more community-based care as an alternative to institutional care, the Optional Medicaid PCS Program continues to play an important role in ensuring that people with disabilities remain in the community (Summer & Ihara, 2005). A second way to receive personal care, and additional services, is through waivers.

Medicaid 1915(c) Waiver Program

Since 1981, states have used authority under Section 1915(c) of the Social Security Act to request a waiver of certain federal Medicaid requirements, including state-wide program coverage, to establish HCBS ‘waiver’ programs (Miller, Ramsland, Goldstein, & Harrington, 2001). These state waiver programs receive federal funding to match state funds allocated for the program and allow states to provide a wide range of HCBS to participants who would otherwise be in an institution (Muramatsu & Campbell, 2002). Services include optional Medicaid benefits such as personal assistance and services not otherwise covered by the Medicaid program, such as home modifications (Kitchener, Ng, & Harrington, 2005).

The Medicaid 1915(c) waiver program offers federal matched funding for non-institutional services, including but not limited to, personal care. Federal waiver programs allow states discretion in determining what populations will be served and which services will be allowed. Target populations for the waiver programs include: aged/disabled, ICF MR/DD, disabled/ physically disabled, AIDS and AIDS related care,

mental health, TBI/head injury, and special care for children. Federal stipulations of the waiver require that room and board is not covered by Medicaid and that the cost of providing HCBS must be *cost-neutral* to receiving services in an institutional setting (AHCA, 2005). In 1982, only six states participated in the 1915(c) waiver program, yet by 1997, every state had implemented a waiver program for at least some subgroups of individuals with disabilities (Miller, Ramsland, & Harrington, 1999). While states annually report waiver participation and expenditures by service, in a first study of its kind, LeBlanc, Tonner, and Harrington (2001) specifically analyzed PCS in waivers. That study reported that by 1998-1999, 26 states offered the Optional State PCS Program, while 45 offered personal care via the waiver(s) (Leblanc et al., 2001). Nationwide, the PCS program was larger, while the HCBS waivers were the more popular administrative mechanism, possibly because it more reliably controls growth (Leblanc et al., 2001). Between 1999 and 2002, the national number of personal care waivers rose by 21 percent (from 131 to 158), helping to spur an increase of 82,024 in waiver participants receiving personal care, and a 45 percent growth in expenditures for this waiver service (Kitchener, Ng, Carrillo, Miller, & Harrington, 2007).

Home Health Program

For Medicaid participants other than those eligible for institutional care, Medicaid home health nursing services are optional. States can vary the amount, scope and duration of benefits offered so long as they remain sufficient to reasonably achieve their purpose and remain the same for all eligibility groups. However, state-to-state variability in the provision and implementation of PCS is significant (Kitchener et al., 2005). All states offer Medicaid home health care but such services are limited in some states.

Home health benefit services are usually short-term and include medical services such as skilled nursing care, rehabilitation, respiratory and physical therapies. Home health is typically short-term, usually following an acute care stay in the hospital and requires home health aides to provide any additional services beyond medical care, such as personal care assistance with basic activities, unlike waiver and PCS programs that allow home attendant services or independent providers to assist with ADLs. Limited data is available on this short-term Medicare benefit.

State-only funded HCBS Programs

State-funded programs vary in size, scope and funding method (Summer, 2001), with some being funded through general state revenue (taxes) and others using methods such as state lottery revenue or tobacco settlement monies. A recent report suggested that the advantage of state-funded HCBS is that they are not constrained by federal regulation and can cover people who might not otherwise be eligible for support (Summer, 2001). Wiener, Tilly, and Alecxih (2002) found that state-only funded HCBS programs tend to be used to supplement Medicaid funding. They studied the LTC system of 7 states (Alabama, Indiana, Kentucky, Maryland, Michigan, Washington and Wisconsin). Out of these, all had state-only funded programs although only Washington, Indiana and Kentucky's were large programs that serve over 10,000 people (Weiner et al., 2002).

The Older Americans Act

The Older Americans Act (OAA) is an important mechanism for providing HCBS for older people and their families by the establishment of the Administration on Aging (AOA) within DHHS. While funding for the OAA is small compared to the major source

of LTC funding (Medicaid), it provides a safety net for people who might otherwise “fall through the cracks” in LTC provision because their income is too large to be Medicaid eligible but they require non-Medical support (Kassner, 2001). Unlike Medicaid HCBS waivers, states do not have to apply to receive federal funding. Title III funds are primarily allocated according to the number of people aged 60+ in each state and all people 60 years of age and older are eligible for OAA services. States participating in Title III are required to set up a State Unit on Aging (SUA) to develop a 2-4 year statewide aging plan covering OAA programs. Many states have divided the state into local Area Agencies on Aging (AAAs) to administer OAA programs (there are 13 states and Territories that have single planning areas as part of the 56 SUAs and 655 AAAs in the US) (Administration on Aging, 2007).

Federal Grants to States

On February 1 2001, President Bush announced ‘The New Freedom Initiative’ (NFI) a cross-governmental policy and funding program that aims to remove barriers to community living for people with disabilities and provide additional momentum to efforts to comply with the ADA. The Department of Health and Human Services (HHS) oversees many programs that aim to help people to live in the community. One of the key agencies within the HHS that has undertaken this work is the Center for Medicare and Medicaid Services (CMS, 2007). The CMS administers a grants scheme called ‘Systems Change Grants’ which is part of the NFI. The overall aim of this grant program is to enable children and adults who have disabilities to: live in the most integrated setting appropriate and to have choices about where they live, their service providers, and the way services are delivered to them (CMS, 2007). There is variation between states in the

way that grant-funded activities are targeted. Some activities are statewide, while others focus on a specific geographic or population groups. Some states have linked the activities between Systems Change Grants with activities funded by grants from other sources (including other Federal grants).

There have been 18 different sorts of grants available to state agencies, 2 other types (Nursing Facility Transitions, Independent Living Partnership and Family to Family Health Care Information and Education Center grants) were available to other state-level organizations (Kitchener et al., 2004). Several states have been awarded 10 different types of grants (Massachusetts has received 11 different awards but one of these was a supplemental 'Real Choice' grant in 2002). The total amount awarded to states varies from \$50,000 to over \$11 million (Wisconsin) and the mean average total award to states was \$3,517,000 (Kitchener et al., 2004).

CMS also organizes projects to support people with disabilities to join or re-join the workforce. These initiatives (which include grants such as Medicaid Infrastructure Grants) are part of the Ticket to Work and Work Incentives Improvement Act (1999). CMS also has an initiative to develop the long-term care workforce called the 'Demonstration to Improve the Direct Service Community Workforce'. This competitive grant program for states was launched in 2003. The demonstration program aims to help states develop programs to increase the pool of direct care service workers through recruitment and retention strategies. However, these initiatives are not included in this case study.

Research and Demonstration Waivers

There are different sub-groups of HCBS waivers, for example 1915(c) ‘model’ waivers are intended to allow states to test new HCBS and have an upper limit of 200 slots. Programs authorized under Section 1115 of the Social Security Act allow experiments, pilot or demonstration projects that promote the objectives of the Medicaid policy and may develop innovative HCBS (e.g. consumer directed HCBS) (Kitchener et al., 2004). For example, the ‘Cash and Counseling’ and Independence Plus initiatives allow states to develop consumer-directed HCBS using either 1115 or 1915 (c) waivers (Kitchener et al., 2004).

Personal Care Services Delivery Models

States provide home and community-based PCS through three delivery models: agency-direction, consumer-direction, and independent providers. Some state programs offer a single delivery system, while others offer beneficiaries a choice between agency model and consumer-direction, or agency model and independent provider and, while the agency-directed model has historically been most common, the consumer-directed model is rapidly increasing in popularity (Levinson, 2006). The Department of Health and Human Services (HHS) Office of Inspector General describes the three delivery models as follows:

- 1) “In the agency-directed model, a home health, personal care, or other licensed agency employs and pays attendants. Agency employees select attendants to provide services to eligible beneficiaries, set attendants’ schedules, and provide substitute attendants. The agencies pay attendants an hourly wage and bill the state Medicaid programs for the services provided (Levinson, 2006)”.
- 2) “The defining characteristic of the consumer-directed model is that the consumer (i.e., Medicaid beneficiary) or his/her representative has more control over the services received and when, how, and by whom the

services are provided. Consumers retain varying levels of responsibility (e.g., hiring, training, scheduling, and paying attendants) in the programs that use the consumer-directed model. Employment and payment arrangements vary (Levinson, 2006)."

3) "In the least common delivery model, individuals apply to the State to enroll as independent providers. They then bill the state directly for the personal care services they provide. The programs that offer this model vary in terms of how consumers select their attendants. Some states maintain a list of independent providers from which consumers select an attendant, while other states utilize a county board or case-monitoring agency to assist consumers in selecting an attendant. However, unlike the consumer-directed model, consumers do not have direct responsibility for hiring, training, scheduling, or paying their attendants (Levinson, 2006)."

It should be noted that the growing trend toward consumer-direction extends beyond the model described in 2) above, with consumer involvement in policy development, local program management and quality assessment comprising important new elements (Eiken, 2004). Taking note of the trend, some states are making efforts to involve program participants, advocates, and family members in the decision-making process to improve participants' experience with LTC systems overall (Eiken, 2004). As a result, these states have implemented common factors in systems reform, placing the client at the center of all planning activities delivered by PCS agencies.

Motivations for hiring providers through the consumer-directed provider model include deficiencies in both availability and capability of agency workers, particularly in rural areas, where they may not be available to provide care outside normal business hours and may not be permitted by their employer agencies to transport clients or assist them with medications (Kassner, 2006). Older people's preference for consumer-direction is expressed in a 1997 survey conducted for the American Association of Retired Persons (AARP) which found that 76 percent of people 50 and older would prefer to manage their own home care services rather than receive services managed by an

agency (Kassner, 2006). A later survey in 2002 of people 50 and older with disabilities found that only 15 percent preferred agency-directed services to alternative models (Kassner, 2006). While legally responsible relatives, such as spouses and parents of minor children, are prohibited from serving as formal PCS providers, findings from a California program show that client satisfaction is improved when relatives, friends, and neighbors provide services. Use of this workforce cohort also helps address the issue of the limited supply of attendants (Benjamin, 2001). Finally, the choice to employ independent workers, including family members, is a factor contributing to reduced nursing home use for those dependent on human help (Dale & Brown, 2006) and for many, where available, it is the preferred option.

Olmstead and Strategic Planning

The 1999 U.S. Supreme Court decision in the Olmstead case (Olmstead v. LC, 527 US 581, 1999) held that unjustified institutionalization constitutes discrimination in violation of the 1990 Americans with Disabilities Act (ADA) (42 USC, Public Law 101-336). Because the ADA applies to all public bodies and the use of public funds, it has implications for the way that states provide publicly funded Medicaid services to people with disabilities. The judges in Olmstead suggested that states demonstrate compliance with the Olmstead decision by producing formal plans for increasing community integration. Overall, studies report three major strategies used by states to develop HCBS: (1) legislative action (policy and budgetary changes); (2) market-based approaches (information enabling consumer choice and creating demand for HCBS); and (3) fiscal and programmatic linkages (improving co-ordination between services) (Crisp et al., 2003).

Since 1999, over 600 Olmstead-related complaints have been filed against state agencies claiming people have not received services in the most integrated setting (Kaiser Family Foundation, 2004). There have been 62 lawsuits filed relating to HCBS and/or community integration since 2000 (Kitchener et al., 2005) and, in at least 20 such cases, states have made settlement agreements involving the development of detailed plans to extend HCBS (Smith, 2004).

REVIEW OF THE LITERATURE

A literature search was conducted using on-line catalogues in health services (e.g., PubMed) and the social sciences (e.g., Business Source Premier). The search began utilizing a query of key words and *MeSH* terms that included: aged, disabled, community-based, waiver program, health policy, Medicaid/home care services, Medicaid/economics, Medicaid/legislation & jurisprudence, state health plans/economics, activities of daily living, eligibility determination, health care surveys, personal health services/ economics, personal care, HCBS, long-term care, personal assistance, community health services/ utilization and Medicaid/ trends, and English only. Search terms were obtained from key research journal articles relating to Medicaid LTC programs, followed by terms to search for “promising practices/ programs”, “better practices”, and “consumer direction” in HCBS, including reports from CMS, and other government and health care foundation sites.

This search strategy retrieved 561 abstracts, which then underwent two levels of analysis. The first stage involved all abstracts being reviewed for content. The second stage of analysis involved a reading of the full-text of those articles and reports meeting

the following inclusion criteria: those providing a national view or comparison of Medicaid HCBS over the last twenty-five years (1980-2005); those providing state level data relating to the delivery of Medicaid personal care and PCS; and, those able to report on evaluation of *better practices* in the provision of HCBS. Because Medicaid HCBS is an applied field of research, peer-reviewed full-text articles are the main resource of literature being reviewed, followed by key reports that focus on various aspects of HCBS and personal care specifically.

As noted earlier, CMS (2006) has created a repository of *Promising Practices in HCBS* to highlight state efforts, and to disseminate timely information on program and policy innovation. Produced by the Thomson/Medstat Research and Policy Division (*Medstat*), these reports (CMS, 2006) are two to three pages in length, although some are longer to provide additional detail or case studies. The seventy-nine reports highlight promising practices in HCBS and are discussed in this review under the section of *better practices* in each section where they are relevant.

Results included a synthesis of seventy-six full-text articles and thirty-eight reports (see Table 2), for a total of one hundred and fourteen.

Table 2. Literature Review Summary

Key Themes	Articles	Reports	Total
Home and Community-Based Services	30	6	36
<i>Better Practices</i> in HCBS	18	29	47
Personal Care Services	27	3	30
<i>Better Practices</i> in PCS	1	0	1
Total	76	38	114

Thirty-six full-text articles and reports meeting the inclusion criteria were identified in the HCBS literature review. Initially, articles were categorized for discussion

by study focus (e.g., multi-state vs. single state), and by type (e.g., descriptive study design vs. regression analysis design). This strategy proved to be a difficult review structure, due to many full-text articles overlapping into multiple categories. Then, it was replaced with a framework of the four main category themes, relevant in health services research literature (Harrington & Estes, 2004) discussion and review: organization and policy, cost, access, and quality (see Table 3.).

Table 3. HCBS Literature Review Summary

Study Content	Articles	Reports	Total
Organization & Policy	11	2	13
<i>Better Practices: O & P</i>	3	14	17
Cost	10	3	13
<i>Better Practices: Cost</i>	10	2	12
Access	7	0	7
<i>Better Practices: Access</i>	1	11	12
Quality	2	1	3
<i>Better Practices: Quality</i>	4	2	6
Total HCBS	30	6	36
Total Better Practices: HCBS	18	28	46
Total HCBS + Better Practices	48	35	83

Summarizing the literature within these domains allows a clearer explanation of the HCBS literature over the past twenty-five years, and focuses on content most often examined within health services research. While there remains some overlap, and all of the literature in this section examines management of HCBS programs, they are coded here by primary concern. For example, an article on waiver expenditures and participants overlaps both the cost and access categories, and is coded under cost for discussion when that is the major study concern focus.

Organization and Policy

Organization and policy is best understood from a historical perspective. There was much debate in the early twentieth century (1920s) addressing the question of an

alternative to institutional care. Benjamin (1993) describes home care policy development and reform at a time when early studies and debate centered on the treatment of chronic illness. Kitchener and Harrington (2004) contribute an institutional analysis of organizational change and inertia in the field of LTC in the US with an overview of the structure of the industry. Their paper provides an historical analysis concentrating on the contest between interests aligned with the ‘traditional’ nursing home model of care versus the HCBS model of care. It demonstrates how a loosely linked collection of institutional reform advocates mobilized against the prevailing forces favoring the nursing home model. Kitchener and Harrington (2004) document how a century of reform advocacy has altered the societal norms concerning patient choice and how both models of care, nursing home and HCBS, were accommodated in the LTC field over time, and how they are at present.

Although reform advocacy has initiated an increase in the growth of Medicaid HCBS, there remain large inter-state variations in the two main Medicaid HCBS programs: PCS and waivers (Kitchener, Ng, & Harrington, 2005). In a national survey of policies used on these program in 2002, Kitchener et al. (2005) report that while the data show a rise in PCS programs and participation; they also reveal falling per-participant expenditures in PCS programs, reduced home health participation, declining annual growth in total HCBS expenditures, and large inter-state variations in program development. In addition, the reported use of cost control policies such as spending caps and large waiver waiting lists in many states suggest a failure to meet the growing demand for Medicaid HCBS (Kitchener et al., 2005).

Various methods have been introduced to examine inter-state variations in LTC organization and policy. Three studies present techniques used to study these issues. In the first, Beynon and Kitchener (2005) assert that the use of attribute sets to rank units of health provision (e.g., states, organizations) against policy goals is an essential task within decision-making and analysis. The classification technique employed, N state Classification and Ranking Belief Simplex (NCaRBS) system, classifies states into strategic groupings. The authors demonstrate that while previous studies recognized the importance of state LTC agencies, as primary payers and regulators of LTC providers, none has explicitly utilized a methodology for measuring the provision of a balance between (traditionally dominant) institutional care, and alternative HCBS, as this study does.

The second method used to explain the diffusion of Medicaid home care waiver programs is variable precision rough sets (VPRS) analysis. Kitchener, Beynon, and Harrington (2004) compared regression analysis using the first VPRS analysis of national data to examine inter-state variation in the Medicaid HCBS waiver program. This demonstrated that VPRS, in addition to an earlier study using the qualitative comparative analysis (QCA) method, offers a robust method for health care research. VPRS analysis of national data provides policymakers relevant information about what attributes are important in locating states in high or low groups on rates of Medicaid waiver program participation and expenditures.

In the third paper, Kitchener, Beynon, and Harrington (2002) introduce the use of the QCA method. QCA combines two research traditions, qualitative inductive analysis, and variable-oriented research, to observe patterns across cases, and to identify and assess

sufficiency (Kitchener et al., 2002). This study identifies the linkages between factors that participants in US state LTC systems perceived as barriers to the expansion of a program that seeks to expand the provision of HCBS. The primary aim of the study was to refine the understandings of HCBS development found in previous studies on the innovation diffusion in healthcare by identifying from case study data, the causal paths that lead to a focal outcome.

Findings indicate that in states with the three necessary conditions, three different combinations of attributes push the state toward low per capita spending on HCBS waiver programs (Kitchener et al., 2002). The primary concern of the study was that, contrary to the intention of federal policy makers and the wish of HCBS advocates, after 20 years of the HCBS waiver program, institutional care still consumed 75 percent of Medicaid LTC dollars (Kitchener et al., 2002).

Comparisons of states' administrative structures can also highlight the variation, and complexities, involved in states' delivery of HCBS. Utilizing case studies, Wiener, Tilly, and Alexih (2002) analyzed how seven states address the major issues in the supply, administration, organization, and financing of HCBS. The overall goal of the project was to study selected programs to assess their effects on quality of care, quality of life, and the move toward increased consumer direction in the field (Wiener et al., 2002). Each state faced unique challenges to program implementation in the 1980s and 1990s, when the economy was strong. One overall issue highlighted by the authors was whether the states had the ability to sustain program growth with the questionable fiscal situation following the downturn in the economy at the turn of the century.

As the Medicaid LTC programs have grown, states have examined methods for controlling LTC costs and ensuring appropriate utilization, and are discussed here as an organization and policy issue. Findings have built a case for federal Medicaid regulations prohibiting states from making the need criteria and the assessment procedures more stringent for HCBS applicants than those for nursing facility admissions (Tonner, & Harrington, 2003). One central feature of state LTC programs is that of screening and assessment to determine a client's need for services (not including the financial eligibility criteria). Under federal Medicaid guidelines, states have flexibility in determining the need for LTC services because the minimum need criteria are not specified in statutes or regulations. Wide variability in minimum need criteria, screening methods, and forms creates potential inequities in access to LTC services across and within states.

Tonner and Harrington (2003) examined screening procedures for nursing facilities and HCBS 1915(c) waiver services for elderly and disabled populations in each state in 1999, to identify the minimum need criteria to be eligible for both nursing facility and home and community-based services. The study reports that preadmission screening procedures for nursing facility and HCBS programs varied widely between and within states, showing that in some states more restrictive screening procedures may limit access to HCBS.

Miller, Ramsland, and Harrington's (1999) descriptive study documents trends and issues in the Medicaid 1915 (c) waiver program over a 15-year period (1984 -1999). This shows the substantial contribution the waivers made to states' efforts to transform their LTC systems from institutional to community-based. Utilizing financial reports (HCFA Form 64 and 372) patterns of data regarding the use of 1915 (c) services by target

group were examined. Policy themes that emerged from the study included: variation in availability of the program by disability group, state decisions related to the provision of community-based LTC, and evidence on effectiveness. Community-based LTC expenditures in the time period studied showed that relative to 1915(c) expenditures, the rates of growth for personal care and home health care have been much more moderate; this despite an increase in the number of states offering personal care as an option.

Consumer Direction

A recent development in the delivery of HCBS has been the emergence of programs that give clients greater control over services (Benjamin, 2001). Consumer-direction (CD) can help ensure that individuals receive services tailored to their needs and preferences. CMS describes consumer directed services as *self-directed* services. In the repository of promising practices, CMS highlights five states offering consumer-directed programs with such practices as maximizing participant control over services (OR); facilitating culturally competent self-determination (MA); increasing control over personal attendants (CO); establishing a back-up support system when a person's attendant is absent (CA); and offering individual budgets for Medicaid waiver services (WY).

Consumer direction in system planning, policy development, local program management, and quality assessment was documented in a multi-state case study (Eiken, 2004). The eight case study states (CO, MI, NH, OR, PA, SC, VT, WI) made special efforts to involve program participants, self-advocates, and family members in the decision-making process to ensure that the reform would improve participants' experience with the LTC system (Eiken, 2004). The results were that these states

implemented common factors in systems reform. One design feature that has shown to be an essential component of systems reform across the disability spectrum in LTC is *person-centered (consumer-directed) services*, those that place the person at the center of all planning activities.

Cost

Cost effectiveness of Medicaid HCBS is the focus of several studies examining various broad expenditure concepts in LTC not included in the previous organization and policy section. Concepts such as: *budget neutrality* (e.g. average Medicaid expenditures for beneficiaries no greater than they would have been without the waiver); *resource allocation* (e.g. where the funding goes, as in the trade-offs between economic, ethical and social criteria for decision-making); the *woodwork effect* (e.g. a concern that new beneficiaries come onto a program “*out of the woodwork*” because of a change in program rules for the target population); and, the concept of *cold bed rule* (e.g. which required states to demonstrate that adequate institutional capacity would exist “absent the waiver”). The following studies drew on these expenditure concepts and, by comparing the cost of HCBS and institutional care, they offer important information for policymakers faced with the competing challenges of state budget deficits and pressures to expand HCBS.

In a review of the most recent evidence on the cost-effectiveness of non-institutional LTC services, Grabowski (2006) confirms that state and federal policymakers have considered the expansion of non-institutional services as a mechanism that both increases client welfare and lowers costs. He discusses the woodwork effect as a “moral hazard problem”, whereby publicly financed HCBS substitute for informal

services previously provided by family members and friends (Grabowski, 2006). Program administrators have found it difficult to structure coverage such that only individuals who otherwise would have entered nursing homes use HCBS. Grabowski (2006) asserts that if targeting were perfect, then the non-institutional treatment model need only be marginally less costly than the institutional model to generate savings. Due to targeting not being perfect, savings from HCBS need to increase to cover the increased costs associated with the *woodwork effect*.

Kitchener, Ng, Miller, and Harrington (2005) reviewed previous cost effectiveness studies and used the most recent available data (2002) to present three per-participant expenditure comparisons between Medicaid HCBS waivers and institutional care: 1) program expenditure (waivers vs. the comparable level of institutional provision); 2) total Medicaid expenditure (program plus other Medicaid expenditure); and 3) estimated total public expenditure (Medicaid expenditures plus state and federal supplemental income payments). The paper presented two main sets of findings from the comparative analysis. First, it elaborated on existing knowledge of variation in per participant cost profiles of different waiver target groups (e.g. elderly and disabled), and estimated that when compared with Medicaid institutional care in 2002, HCBS waivers produced a national average public expenditure saving of \$43,947 (Kitchener et al., 2006). Six issues for future research are presented, along with explanation of the barriers posed by opponents to expansion of HCBS.

Miller, Harrington, and Goldstein (2002) explored state variation in expenditures for Medicaid HCBS for the period 1990-1997. Utilizing a random effects panel model, the authors examined the relationship between state demographic, supply, economic,

programmatic, and political factors and states' Medicaid community-based care expenditures. The results showed that, although states increased provision of services, significant state-level variation was evident. Expenditures were positively associated with state per capita income, regulation of nursing home bed supply, and the number of Medicare home health users but were negatively related to nursing home bed supply, concluding that the most consistent relationships amenable to policy intervention related to state fiscal resources and LTC supply regulation (Miller, Harrington, & Goldstein, 2002).

Efforts to evaluate the cost-effectiveness of HCBS programs utilized historical trend data to project what nursing home and total aggregate LTC costs might have been in the absence of these programs. In 1995, average monthly spending per capita for clients receiving services in "aged/disabled" HCBS waivers across all states with waivers was \$485 per month. In contrast, average monthly spending per Medicaid- covered nursing home resident was \$2,426.14, and under the Medicaid PCS benefit, \$589 per month (Doty, 2000).

In designing programs, states operate within certain constraints and particular political environments that shape the public programs they oversee (Kitchener, & Harrington, 2005). Miller, Ramsland, Goldstein, and Harrington (2001) assert that the most robust findings across studies are the positive relationships between the state economic environment, demand, and state use of local administration of the Medicaid program and various forms of expenditures. In a multivariate regression study using the state as the unit of analysis Miller et al. (2001) examined the use of Medicaid 1915 (c) HCBS waivers to reconfigure state LTC systems. Utilizing a model to identify factors

influencing Medicaid expenditure decisions, they first explored three forms of Medicaid LTC expenditures: per capita LTC expenditures; per capita 1915 (c) waiver expenditures; and the share of LTC dollars targeted to 1915 (c) waivers. Secondly, their study empirically explored the effect of certain state features suggested in case studies to influence LTC system configuration and related expenditures.

Miller (1992) describes the growth of the waiver program during its first ten years of operation, documenting growth of service expenditures under the waivers from \$1.7 billion spent in 1991, compared with \$3.8 million in 1982, when only six states were participating in the program. In 1982, the first year in which states first had the option to provide waiver services, the average expenditure for home health services was 1.2 percent of LTC dollars. While no expenditures for the personal care option were reported in 1982, by 1990 state expenditure for home health had grown to 2.8 across states, with approximately one-half of the states providing personal care as an optional Medicaid service (Miller, 1992).

An early descriptive evaluation of two specific waiver programs (California and Georgia) examined the data and techniques needed to assess the ability of programs to achieve budget neutrality (Vetrees, Manton, & Adler, 1989). This demonstrated that, for these programs to succeed at budget neutrality, it is necessary to target a narrow range of inexpensive services to people for short periods of time, findings comparable to an earlier comparison (Laudicina & Burwell, 1988).

Better Practices in Cost/ Financing of HCBS

In a review of the cost-effectiveness of non-institutional LTC services, Grabowski (2006) examines the cost-effectiveness of recent LTC programs, including waivers and

consumer-directed HCBS. Generally the care models examined were found to be associated with increased costs, but greater client and caregiver welfare. While consumer-directed care was identified as a mechanism toward providing services more efficiently (Grabowski, 2006), the assertion is made that recent evaluations of cost-effectiveness have relied on potentially confounded research designs, leaving open the question of whether the findings relate to the programs or biased selection across the treatment and comparison groups. The large expansion in HCBS models reflects a strong societal preference for these services. Grabowski (2006) suggests that future demonstrations with rigorous study designs will be necessary to measure cost-effectiveness in HCBS.

Cash and Counseling

Cash and counseling demonstration and evaluation arose in late 1994 and early 1995 (Doty, 2000). The impetus for the demonstration can be traced to the LTC proposals included in President Clinton's 1993 healthcare financing reform plan (Doty, 2000). The proposed legislation would have allowed states, at their discretion, to offer self-directing consumers maximum choice and control by providing benefits in the form of a cash allowance in lieu of specific defined services (Doty, 2000).

In 1994, a study by Flanagan (1994), focusing on tax and labor law issues that affected state administration of consumer directed personal assistance programs, included a descriptive overview of twenty-two consumer directed personal assistance services programs in sixteen states. Flanagan has provided research and technical assistance to all of the "Cash and Counseling" states in designing the fiscal intermediary services,

awarding contracts to fiscal intermediary organizations, and monitoring their performance after implementation (Doty, 2000).

Medstat/CMS promising practices reports include the cash and counseling projects of Florida, New Jersey and Arkansas - a three-state demonstration that uses an experimental design to evaluate the impact of a cash payment program that offers support services to help people with disabilities use cash payments (CMS, 2006). The Assistant Secretary of Planning and Evaluation in the U.S. Department of Health and Human Services (DHHS) and the Robert Wood Johnson Foundation sponsor the demonstration. CMS, also in the U.S. DHHS, granted the three states the demonstration authority necessary to conduct this project (CMS, 2006) by Section 1115 of the Social Security Act.

In a study to assess Medicaid consumers' interest in a the consumer-directed cash option for personal care and other services, in lieu of agency delivered services, Mahoney, Simon-Rusinowitz, Louthlin, Desmond, and Sequillace (2004) offer survey outcomes for over two thousand participants from the states of Arkansas, Florida, New Jersey and New York (New York dropped out of the cash and counseling demonstration project after being included in this survey study). The authors concluded that there is a significant interest in the cash option, although interest varies among subgroups of consumers. The principal findings showed that the cash option interest was positively associated with experience hiring and supervising workers, more severe levels of disability, having a live-in caregiver, living in Florida, and minority status (Mahoney et al., 2004). Age of the client was also a significant factor, with consumers in their thirties and forties showing more interest in the program than those over forty. These evaluations of the case and

counseling option offer lessons about how to implement programs in other states interested in offering consumer-direction.

Access

With passage of the Americans with Disabilities Act (1990), and the Supreme Court Olmstead decision (1999), policymakers are increasingly forced to examine factors affecting expansion of HCBS. Previous empirical work has examined state-level factors related to rates of use and expenditures for Medicaid 1915 (c) waiver services (Harrington et al., 2000; Miller et al., 2001). More recent findings document variation by disability in state predictors of Medicaid 1915 (c) use and expenditures (Miller, Kitchener, Elder, Kang, Rubin, & Harrington, 2005). Using state-level data for the period from 1992-2001 to estimate fixed-effects panel models, Miller et al. (2005) compared state predictors of waiver utilization and expenditures for waivers serving both older and working-age individuals. Findings show a greater share of LTC dollars supports community-based-care for individuals with intellectual and developmental disabilities, relative to older and working-age persons with primarily physical disabilities.

Kitchener, Ng, Miller and Harrington (2005) present the latest program trends in the three Medicaid HCBS programs and report a national survey of cost control policies used on waiver programs in 2002. The findings show slowing annual rates of participation growth on individual programs, widespread use of cost controls on waivers including waiting lists, and the persistence of large interstate variations in Medicaid's provision of these services (Kitchener et al., 2005).

In a longitudinal analysis of state variation in expenditures and utilization for three HCBS programs (waiver, home health, and personal care), Kitchener, Carrillo, and

Harrington (2003/2004), documented positive state-level factors related to HCBS participants including: higher percentages of aged people; greater incomes per capita, and a larger supply of home health agencies. The analysis presents time series regression models that estimate factors associated with intra-state variation in waiver participant and expenditures from 1992-1999 (Kitchener et al., 2003/2004), though reliable and comparative target group data is difficult due to there being no longitudinal participant data for the personal care and home health programs.

In a descriptive survey study examining the met and unmet need for Medicaid PCS and HCBS waivers across the states, Harrington, LeBlanc, Wood, Satten, and Tonner (2002) confirm a number of barriers for the expansion of HCBS including an inadequate supply of HCBS providers, limited state legislative support for the programs, and federal regulatory barriers such as restrictions on need criteria. Study results showed that, in spite of wide variations in total HCBS participants per capita, 42 states reported inadequate waiver slots and waiting lists. Even in states with the highest participant rate per capita, state officials reported waiting lists for the HCBS waiver programs and many target groups that were not adequately covered by the current HCBS waivers (Harrington et al., 2002). The authors support further research to address the questions of: how to ensure that Medicaid participants are offered a choice between institutional and HCBS services and have access to appropriate services in the least restrictive environment; and, how to ensure equity in access to PCS and HCBS services across states and across target groups (Harrington et al., 2002).

Many of the first 1915(c) Medicaid HCBS waivers were targeted toward the aged and disabled or individuals with mental retardation or developmental disabilities

(MR/DD). In more recent years, state waivers have targeted persons with a variety of conditions and chronic disorders, such as physical disabilities, AIDS, acquired brain injuries, and mental illness (Miller et al., 1999; Harrington et al., 2000). In a study examining access to the 1915 (c) waiver programs (1992-1997) Harrington, Carrillo, Wellin, Norwood, and Miller (2001) report an unequal distribution of HCBS expenditures across target groups. Individuals with developmental disabilities were 39 percent of participants, but used 77 percent of the total \$7.9 billion waiver expenditures in 1997, while the aged and disabled made up 58 percent of the waiver participants but received 21 percent of expenditures (Harrington et al., 2001). The evidence suggests that while the 1915 (c) HCBS waiver programs have been successful in expanding HCBS, greater efforts are needed in two arenas; the continued shift away from the heavy reliance on institutional care; and, growing need to focus on equity issues for participant groups in terms of access to waivers, services, and expenditures (Harrington et al., 2001).

In a study documenting wide interstate variation in organizational oversight and program policies for the waivers, LeBlanc, Tonner, and Harrington (2000) describe structural barriers to the expansion of HCBS waivers. The authors give an historical time line on the study of waivers from their inception (Miller, 1992), the state and national trend data (Miller, Ramsland, & Harrington, 1999; Harrington et al., 2000), and cost-effectiveness data (Vertrees et al., 1989; Alecxih et al., 1996), and aimed to examine issues of program administration (LeBlanc et al., 2000). Findings showed program structures that limited growth, such as cost ceilings and hourly limits on services, and policy options were offered for consideration (e.g. for states to use the same financial

eligibility criteria for institutional care and HCBS to reduce institutional bias) (LeBlanc et al., 2000).

In a study using trend data over a six-year period, Harrington, Carrillo, Wellin, Miller, and LeBlanc (2000) examine an array of state-level factors associated with the number of state participants in the 1992-1997 period. The analytical model utilized tested the effects of socio-demographic, economic, political, public policy, and health service factors on waiver participants. Although previous studies had examined factors relating to spending on HCBS, this was the first study that examined the factors associated with waiver participants in states (Harrington et al., 2000). Two separate regression analyses, utilizing HCFA Form 372, and data gathered from officials of each state for each year, examined trends and predictors of State Medicaid HCBS waiver participants and expenditures from 1992-1997. State waiver participants were positively associated with those over 85 and over, personal income, residential care beds, and inpatient users and negatively associated with home health regulation and nursing home beds (Harrington et al., 2000). The results informed policy makers and clinicians about which factors could be changed to expand the number of state waiver participants.

Better Practices in Access

Better practices in access to HCBS includes: states that incorporated a population needs assessment; consumer involvement, including informed choice, and single-point of entry; linkages such as housing and transportation; workforce issues, and caregiver support. All of these issues affect a consumer's ability to have access to HCBS.

Consumer Involvement, Informed Choice, and Single-Point of Entry

Eiken et al. (2004) assert that single access points to obtain information and advice, and access to services and supports are essential components of systems reform. In a survey of states with single entry point systems, Mollica and Gillespie (2003) describe single point of entry as a system that enables consumers to access long-term and supportive services through one agency or organization. In their broadest forms, these organizations manage access to one or more funding sources and perform a range of activities that may include information and assistance, preliminary screening or triage, nursing facility preadmission screening, eligibility determination, monitoring, and reassessment (Mollica & Gillespie, 2003). Thirty-two states and the District of Columbia reported 43 single entry programs, with nineteen reporting none as of the survey year (2003). Common elements were identified across single entry programs including, those that serve two or more populations; control multiple funding sources; and require care managers to have a minimum of a bachelor's (Mollica & Gillespie, 2003).

Reports on consumer involvement, person-centered informed choice and single-point of entry improved Medicaid access for a number of populations (CMS, 2006). Seven separate reports (CMS, 2006) on access describe: single-point of entry options for people discharged from hospitals with simplified access to nursing home alternatives (CO); continuity of care for HIV ex-offenders (RI) and the homeless; targeted access to LTC services on Indian reservations (MN); simplified access for HCBS (IL, CO, NJ), and resource centers dedicated to offering single-point of access (WI).

Linkages

Linkages services, such as housing and transportation, while not provided as part of Medicaid HCBS, have been found to be instrumental in the access of services for older

adults and younger disabled who require personal care. CMS (2006) *promising practices* reports a number of state measures that offer linkages services. They include: home ownership through coalitions (IL); accessible housing registries (MA); and housing support systems for people with disabilities (NH, IN, WI, & MA).

Workforce

Workforce issues are related to empowering workers to improve the quality of HCBS. The repository of promising practices (CMS, 2006) highlights four states that have initiated promising programs in support of the workforce, with some states having multiple programs. They include: creating jobs for people with disabilities (NY); creating direct-care worker associations (NY); improving recruitment and retention of direct support workers (VA); recruiting direct service professionals in a competitive environment (MA); and a similar program, the right people for the right job (IW): recruiting direct-care workers for HCBS.

Caregiver Support

Caregiver support, like workforce, is directly related to consumers' access to HCBS. States have recognized the importance of supporting both formal and informal caregivers in support of consumers remaining in the community. Promising practices for caregiver support (CMS, 2006) highlight six states that focus on various aspects of the caregiver role, some with multiple promising programs (WA). They include: resource counseling and financial assistance for informal caregivers (PA); facilitating culturally competent self-determination (MA); family-directed support network for families of people with disabilities (UT); state sponsored endowed trust fund (WA); supporting

caregivers in ethnically diverse communities (WA); and offering vouchers caregivers use to pay for services (GA).

Quality

Few states have made monitoring quality of care and quality of life a major priority (Gage, Wiener, Brown, Khatutsky, Moore, and Osber, 2004). Building on an earlier review on quality in HCBS (Booth, Frailich, & Nonemaker, 2002), Gage et al. (2004) propose relevant research questions for quality assurance in HCBS such as, “How can quality of care and quality of life for HCBS be measured?” “How does quality of care and quality of life compare to institutional care?” And, “Does training affect quality of care?” (Gage et al., 2004).

The availability of mandated, uniform clinical data in all nursing homes and home health agencies serving Medicaid beneficiaries has facilitated the public reporting of some, limited, comparative quality data between institutional and HCBS (Mor, 2005). In a study on improving the quality of LTC with better information, Mor (2005) examines the quality indicators mandated for reporting by Medicare and Medicaid-certified nursing homes and home health agencies. The limited focus on quality in the HCBS literature illustrates the difficulty in defining what definition of *quality* one is referring to.

In a literature review on quality management and improvement practices for home and community-based care, Booth, Frailich, and Nonemaker (2002) describe the multiple and sometimes conflicting definitions of quality, the lack of uniform data, and absence of a focal point for accountability. Commissioned by CMS, their literature review is organized to correspond to the basic components of a quality assessment and improvement process. The review examines the underlying infrastructure necessary to

support quality of care in HCBS. It documents approaches for measuring the performance of HCBS providers, and their effect on the health status and well being of clients (Booth et al., 2002). The authors highlight challenges to quality improvement where less is written and understood about state oversight of highly fragmented systems of care where providers have less influence on the outcome.

A strong case has been built for the study of quality in HCBS, in addition to examining cost and access (Leblanc et al., 2000; Harrington et al., 2002). In HCBS, however, states are not required to use a uniform assessment instrument for determining program eligibility, assessing care or service needs, or developing service plans (GAO, 1996). Most states have modest quality assurance activities, and rely heavily on informal mechanisms to assure quality (Wiener, Tilly, & Alexih, 2002).

An earlier paper, offering perspectives from multiple stakeholders, describes the challenges of defining and achieving an acceptable quality of in-home services for older people (Kane, Kane, Illston, and Eustis, 1994). Panel surveys identify key themes important to the stakeholders polled as: case management, accountability, and flexible, negotiated care plans (Kane et al., 1994). The authors state the goals of examining best practices in quality assurance, and ongoing criteria and standards for consumer directed care regardless of the regulatory and case management approaches utilized. Quality is seen as having three steps: establishing the definition of adequate and/or excellent quality; assessing care against those standards; and correcting identified problems (Kane et al., 1994). While *quality of life* is a difficult term to define and measure, Gage et al. (2004) assert that some issues on quality assurance, researched in earlier periods, deserve to be revisited because of changing circumstances.

Better Practices in Quality Related to HCBS

In light of increased demand for HCBS services, and rising public expenditures for them, quality assurance remains increasingly important. The focus on quality is evident in the nine state reports on quality in the CMS (2006) repository of promising practices. They are: an automated provider monitoring system, case management services, and improving responsiveness of service managers to persons' needs (SC); a consumer outcomes survey (WI); incident reporting and tracking system (OH); independent monitoring for quality (PA); mission-based performance indicator system (MI); a report on the quality improvement process (IN); and quality measurement involving volunteer reviewers (MN). Given the difficulty in developing standards for and measuring the quality of HCBS, the practices above indicate that states are increasing the extent of innovative and effective means towards that goal.

PERSONAL CARE LITERATURE

CMS's Medicaid Manual guidance describes state plan PCS as, "a range of human assistance provided to persons with disabilities and chronic conditions of all ages, which enables them to accomplish tasks they would normally do for themselves if they did not have a disability" (CMS, 2005b). Medicaid PCS, defined in Federal regulations at 42 CFR 440.167, are an optional Medicaid benefit provided to individuals who are not inpatients or residents of a hospital, nursing facility, intermediate care facility for the mentally retarded, or institution for mental disease. PCS must be: 1) authorized by a physician in accordance with a plan of treatment or, at the state's option, otherwise authorized in accordance with a service plan approved by the state; 2) provided by a qualified individual as defined by the state who is not a member of the individual's

family; and, 3) furnished in a home or other location outside the home (in the community) (CMS, 2005b).

Twenty-seven full-text articles, and 3 reports comprise the personal care literature review. The literature is divided into four sections for discussion: organization and policy, access, cost, and quality (Table 4).

Table 4. PC Literature Review Summary

Study Content	Articles	Reports	Total
Organization & Policy	15	1	16
Access	8	0	8
Cost	4	1	5
Quality	0	1	1
Total	27	3	30

Emergence of Personal Care

In discussing the history and “re-invention” of personal care, Glazier (2001) states that, “The idea of younger persons with severe disabilities and chronic health care needs receiving paid in-home assistance to prevent institutionalization seemed at first a novel one”. In-home attendant care, later termed “personal care assistance” (now synonymous with personal care), had evolved as a non-medical solution to a problem that had initially been conceived as a medical need, but one that had proven too costly to be served within the health care system (Glazier, 2001). Tracing the history of personal care offered through regional centers of The National Foundation for Infantile Paralysis (March of Dimes) in the 1950s, to geographically dispersed Independent Living Centers that evolved from the Berkeley Center for Independent Living from the 1960s on, Glazier (2001) articulates the efforts to create an entitlement to personal care at a national level.

In a literature review on personal care, Nosek (1991) describes the models of provision, service delivery, and analysis of policy implications. Others were advocating

strongly toward a national personal care program offering alternative models, including the independent living model of long-term care for persons with disabilities (Batavia, Dejong, & McKnew, 1991; Kemper, 1992; Kennedy, 1993). Documented use of personal care was described for people with disabilities living in rural areas (Nosek, 1992), those with mental illness and mental retardation (Nosek, 1993; Doyle Pita, Ellison Langer, & Farkas, 2001), and those with spinal cord injury (Nosek, Fuhrer, Rintala, & Hart, 1993), further building a case for consideration of a national plan to serve all groups in need with personal care.

Over the past 30 years a gradually increasing number of states have chosen to make personal care an entitlement under their Medicaid program (Litvak, 1998). Litvak (1998) explores personal care policy and documents how interaction between the disability community and elderly community has resulted in beneficial exchanges on the issue of consumer control for older people (WHConA 1995, 2005). From a service available in only a handful of states it has evolved so that there are now personal care services in every state.

Under substantial political pressure from disability rights groups, and not willing to wait for establishment of a national program, several states have used the waiver authority under the Medicaid program to establish their own statewide personal assistance services programs under variations of the independent living model (Doty, Kasper, & Litvak, 1996). These programs have served as a natural experiment on the financing and provision of personal care. Analysis of their structures, functions, and outcomes has provided valuable information (Kennedy & Litvak, 1991).

Case managers can serve a vital role in the coordination and support of personal care for people with disabilities, if utilized to support the client's needs from their perspective, as opposed the historical medical model (Glazier, 2001; Doty, Eustis, & Lindsay, 1994). With a desire for maximum independence and autonomy, models such as the Independent Living Model, are based on an approach to personal care that incorporates a case management model that supports the principles of consumer-direction and self-determination (Gilson, & Casebolt, 1997), while abiding by federal policy with the same goals (ADA, 1990; Olmstead, 1999) of the right to personal care "in the most integrated setting appropriate (Batavia, 2001). Doty et al. (1994) discuss the emerging definition of personal care as a term synonymous with HCBS, as a re-conceptualization of LTC policies, programs and services to take into account the needs of persons of all ages (not just those aged 65 and over) for functional assistance.

Organization and Policy

There is a growing body of national survey and evaluation research indicating that various kinds of equipment, goods and services (EGS) other than one-on-one human assistance from formal and informal caregivers can serve to meet the needs of people with long-term functional difficulties in home and community-based settings (Mahoney, 2005). In a study determining how often assistance reduces or resolves health-related difficulties in everyday tasks, it was shown that equipment by itself is more efficacious than personal assistance, alone or combined with equipment, (Verbrugge, Rennert, & Madans, 1997), demonstrating implications for public health policy incorporating EGS. Services such as housing, while not a part of the PCS program, are a part of the vital *linked* services that are tied in to HCBS. Services such as housing and transportation are

proving to make a difference in the success of HCBS personal care access, and delivery, and are discussed in the Better Practices section of this paper.

Better Practices in Organization and Policy: PCS

Consumer Direction

CD in PCS involves some degree of decision-making about the specific services that program beneficiaries need and want, who will provide the services, how the services are provided, and how providers will be compensated. Overall, 71 percent of states (17 states) allow consumer direction for the PCS benefit. Of those, only three states, Minnesota, New Jersey, and Texas, give consumers the discretion to purchase services within an individual budget (Summer & Ihara, 2005).

The extent to which any consumer has control over the set of tasks associated with consumer direction varies by state. Generally, consumers participate in preparing service plans and in screening, training, and supervising personal care workers. It is less common for consumers to negotiate compensation or to be directly involved in paying providers of care. Only New Jersey allows consumers to assist in payroll management (Summer & Ihara, 2005). The more common approach is to have the state serve as the fiscal intermediary between consumers and providers. This occurs in one-third of the states that make provisions for consumer direction, 5 of the 17 states that do so. Fiscal agents generally take responsibility for tasks such as paying service providers, withholding taxes, and conducting criminal background checks.

Access

Expanding access to paid personal care appears crucial in reducing unmet need, especially among those who live alone and require assistance with ADLs (Laplante, Kay,

Kang, and Harrington, 2004). Estimating unmet need for personal care is the primary focus of a study by LaPlante et al. (2004) who assert that minimizing unmet need is the primary goal of LTC policy, and is a financially achievable goal. Their study estimated the shortfall in hours of personal care, and the adverse consequences of unmet need using a multivariate regression model utilizing data from the National Health Interview Survey on Disability (NHIS-D) from years 1994-1997. The results showed that individuals with unmet need for personal assistance/care with two or more of the five basic ADLs have a shortfall of 16.6 hours of help per week compared with those whose needs are met. The relative shortfall is twice as great for persons who live alone as for those who live with others. People who live alone and have unmet needs fare worse than people with unmet needs who live with others, and both groups are more likely than those whose needs are met to experience adverse consequences, including discomfort, weight loss, dehydration, falls, burns, and dissatisfaction with the help received (Laplane et al., 2004).

Human help is not always the best solution even for those who feel they need it. Sometimes assistive technology is the key, or a combination of the two. Agree and Freedman (2003) conducted a comparison of assistive technology and personal care in alleviating disability and unmet need. Using data from the 1994-1995 NHIS-D, the authors examined differences in reports of residual disability and unmet need by type of long-term care arrangement (assistive technology or personal care). Their assertion is that the relative advantages of assistive technology and personal care are not well understood, in part because most studies evaluate one or the other, but rarely the two together.

The study found that even when differences in underlying disability are accounted for, assistive technology confers no additional benefit in the three dimensions of residual

difficulty analyzed (Agree & Freedman, 2003). Results confirmed that although adults with disabilities using only assistive technology tend to be less disabled than users of personal care, they are more likely to report that a task is tiring or time consuming when they use their equipment. Users of assistive technology are less likely to report a need for any hands-on help than those already using personal care (Agree & Freedman, 2003). While there may be unmet needs that can be better fulfilled by technology rather than personal care, the findings from this study suggest that some proportion of the disabled population may have unmet needs but would not report a desire for personal care.

In an earlier study, Laplante, Harrington, and Kang (2002) estimated paid and unpaid hours of PAS in ADLs provided to adults living at home. Also using the NHIS-D household survey data from 1994-1997, the authors estimated the hours of assistance for both working-age and older adults, a first. Findings estimated that 13.2 million non-institutionalized adults receive an average of 31.4 hours per week of personal assistance in ADLs and IADLs per week, with 3.2 million people receiving an average of 30.7 hours of unpaid help. More person's ages 18-64 received help than those ages 65 and older (6.9 versus 6.2 million), but working-age recipients had fewer hours (27.4 versus 35.9) per week, due in part to less severe levels of disability (Laplante et al., 2002).

The study documented that older persons are more likely to receive paid personal assistance/care, while working-age people rely to a greater extent on unpaid help, offers evidence that some informal help substitutes for formal help, and that paid and unpaid hours increase rather dramatically as the number of ADLs and IADLs increase, as expected (Laplante et al., 2002).

Desai, Lentzner, and Weeks (2001) examined the prevalence, correlates, and negative consequences of unmet need for personal assistance with ADLs among older adults utilizing cross-sectional data from the NHIS Supplement on Aging weighted to be representative of the non-institutionalized population aged 70 and older. The results showed, overall, that 20.7% of those needing help to perform one or more ADLs (an estimated 629,000) reported receiving inadequate assistance; for individual ADLs the prevalence of unmet need ranged from 10.2% eating to 20.1% transferring. The likelihood of having one or more unmet needs was associated with lower household income, multiple ADL difficulties, and living alone. Nearly half of those with unmet needs reported experiencing a negative consequence (e.g. unable to eat when hungry) as a result of their unmet need (Desai et al., 2001). The implication is that, greater, targeted efforts are needed to reduce the prevalence and consequences of unmet need for ADL assistance in elderly persons.

Cost

In a survey of the states that offer personal care programs to older people, findings confirm the variation in LTC systems, and a complexity of options that states use to provide services (Summer and Ihara, 2005). Summer and Ihara (2005) examined program expenditures, services offered, and the types of service providers used in an attempt to understand the choices that states make in choosing waiver programs over the Optional State PCS Program, and for what types of beneficiaries. While data on state spending on PCS programs was available, little had been reported on older Americans receiving benefits through the state PCS programs. Findings revealed that almost 700,000 beneficiaries of all ages received in state fiscal year 2003 (Summer & Ihara, 2005), with

variation across states. The elderly were found to be the largest proportion of beneficiaries of the states reporting complete data on population composition categories.

A multilevel analysis examining the association of state HCBS expenditures with use of formal and informal personal care among non-institutionalized older American aged 70 and older with functional limitations suggests state variation in HCBS expenditures leads to inequitable access to formal personal care, especially among those with high functional limitations (Muramatsu, & Campbell, 2002). Muramatsu and Campbell (2002) conducted multilevel multinomial logistic regression analysis using data from the first wave of the Assets and Health Dynamics among the Oldest Old Survey, combined with data on state HCBS expenditures. Controlling for individuals' demographic, socioeconomic, and care needs factors, persons residing in states with higher HCBS expenditures were more likely to use formal personal care, but not less likely to use informal assistance. State commitment to HCBS, especially the level of funding allocated to HCBS, may also affect those who are not eligible for publicly funded programs (Muramatsu & Campbell, 2002), and by doing so influence the level of services available and the norms and expectations of consumers and providers in the state.

By 1998-1999, 26 states offered the Optional State PCS Program (Leblanc, Tonner, & Harrington, 2001), while 45 offered personal care via the waiver(s). Nationwide, the PCS program was larger, while the HCBS waivers were the more popular administrative mechanism, possibly because it more reliably controls growth, according to Leblanc et al. (2001). This study offers state and national statistics on the number of Medicaid personal care participants and expenditures, and describes how the states vary in their implementation of the two programs. The data supports the findings

that the HCBS waivers account for a smaller proportion of the Medicaid personal care caseload than does the Optional State PCS Program, which by regulation must be offered statewide (Leblanc et al., 2001). The participants and expenditures per capita show the dramatic variation across states in investment in programs offering personal care services, and how only a handful of states account for the majority of participants reached with services and funds spent (Leblanc et al., 2001).

The authors conclude that, were the states to unanimously adopt the Medicaid Optional State PCS Program as a means of providing personal care, the result might be improved access to personal care for larger percentages of low-income individuals (Leblanc et al., 2001). Once elected, the PCS Program must be provided to all eligible individuals with a demonstrable need for personal care, a factor that may prevent additional states from adopting this benefit (GAO, 1999).

Better Practices associated with Cost/ Financing of PCS

In 1989, the World Institute on Disability (WID) received funding from the National Institute for Disability and Rehabilitation Research (NIDRR) in the Department of Education to replicate the national survey of personal assistance programs, as of 1988 (Doty, 2000). This also provided an opportunity to study variation across states in how the Medicaid PCS optional benefit was administered (Doty, 2000). Federal policy analysts contracted with WID to explore why some states had elected to finance personal care services only through a “medical model”, requiring attendant care to be provided by certified home health or licensed homecare agencies, whereas other states permitted or required Medicaid beneficiaries to hire, fire, and supervise their own attendants (Doty, 2000). The WID analysis of the 1988 survey data on attendant care programs found that

46 percent of these Medicaid programs either required or permitted Medicaid beneficiaries to hire and manage their own attendants directly (Doty, 2000). The case studies suggested that cost effectiveness, more than a philosophy of promoting independence and autonomy for people with disabilities, was the primary motivation when states chose to encourage or to require “consumer-directed” modes of service delivery (Doty, 2000). Medicaid beneficiaries aged 65 and older who used PCS who reported having more choice and control over hiring and managing their attendants reported greater satisfaction with their attendant services than did beneficiaries reporting less choice and control (Doty, 2000).

Quality

Kennedy and Litvak (1991), in a report for the US Department of Health and Human Services, surveyed six states for case studies of the Optional State PCS Programs. The study addressed key program policy issues, including: program history and objectives, population served, support services, expenditures, and the relation of personal care to the other state programs.

Results show that consumer choice and satisfaction appear to be maximized when a public program not only permits, but also actively encourages, clients to hire their own attendants directly. That is, when the PCS Program attendants are treated as employees of the client, in contrast to being employees of a home health or home care agency. Or, to acting as independent contractors who obtain their jobs through recommendations from registered nurses, who subsequently provide on-the-job training and supervision. Basically, allowing consumers to hire whomever they wish. The data suggest that when consumers are permitted to hire attendants directly and face few restrictions on whom

they may hire, they tend to favor persons already known to them: family members, friends, neighbors, and individuals who are known to and come recommended by family, friends, and neighbors. The result, for many clients, is an integration of their formal and informal support systems. While consumer satisfaction is an indicator of quality within a program, more current studies are clearly needed to measure and verify quality in the PCS Program.

Conclusion

This synthesis of the literature has described better practices relating to themes of organization and policy, access, cost, and quality of the provision of Medicaid HCBS personal care. In conclusion, the emergence of better practices as a descriptor in the literature is highlighted by a brief evaluative summation of each of the four themes.

Organization and Policy

Studies and reports on organizational structure and policy related to Medicaid HCBS document a continual growth and expansion of Medicaid HCBS. Descriptive articles offer historical perspectives to understand the trends in personal care, and the provision of HCBS over time. There is tremendous inter-state variation in the provision of Medicaid HCBS across the country. There are also many administrative structures involved in states' delivery of HCBS, including differences in need criteria and assessment for eligibility. Better practices in the organization and policy of HCBS describe an emerging consensus of consumer-directed care programs as a move towards system reform and participant satisfaction and autonomy. There are programs that offer informed choices for person-centered decision making, and programs that allow residents to leave nursing homes and receive support in the community. Better practices, such as

consumer-direction, are also evident in the literature on the Medicaid Optional State PCS Programs, even though this program providing personal care has not been singled out for recognition in any *Medstat/CMS promising practices* reports to date.

Cost/ Financing

Studies on cost analysis, cost-effectiveness, and the factors that influence inter-state variation in the provision of personal care through Medicaid HCBS improve our understanding of the issues related to the financing of Medicaid HCBS. They report on budget neutrality, resource allocation, and the cost-effectiveness of HCBS versus institutional care. Studies show that states operate within certain constraints and particular political environments that shape the public programs they oversee. Better practice articles and reports associated with financing Medicaid HCBS programs examined care models that were so far associated with increased costs, but greater client and caregiver welfare. The large expansion in HCBS models providing personal care reflects a strong societal preference for these services. The argument is made that there are potential studies that could greatly improve our understanding of the cost-effectiveness of different LTC models. It has also been suggested that more of the evaluations of the demonstration projects relating to provision of HCBS need to be published in peer-reviewed journals that shape public policy, and not have availability limited to unpublished final reports submitted only to funding agencies.

Access

Large inter-state variations exist for provision of Medicaid HCBS personal care, and have a direct affect on access to HCBS to those in need. Studies on waiver programs document a number of barriers to receiving care, including waiting lists and inadequate

waiver slots. In spite of federal mandates requiring that states provide access for receiving HCBS, there still exists wide variation in which groups have their needs met. Better practice literature in relation to access focus on population needs assessment, single points of entry, linkages services such as housing, available workforce, and caregiver supports. Better practices also report on the improved recruitment and retention of direct care workers and confirm that these issues are directly related to consumers' access to HCBS.

Quality

Few states have made monitoring quality of care and quality of life a major priority, and this knowledge gap is apparent in the limited literature that address the issue of quality. Quality assurance is one of the weakest areas of research emerging from the data on Medicaid HCBS, and yet one of the most important. Most states have modest quality assurance activities, and rely heavily on informal mechanisms to ensure quality.

Better practices in quality related to Medicaid HCBS reports improvements in nine states that have initiated improvements or innovations in the areas of incident reporting and tracking, case management services, responsiveness to consumers' needs, independent monitoring, and outside reviewers for increased oversight. Better practices related to the Medicaid Optional State PCS Program report on consumer-direction, and the increased autonomy consumers report by being able to participate in preparing their own service plans, and in screening, training, and supervising personal care workers.

Consumer advocates highlight the need for screening before people go into nursing facilities as one way to support Olmstead and offer critical HCBS to consumers in their own homes. CMS's Minimum Data Set shows the percentage of persons in

nursing facilities who were admitted directly from their homes and apartments with no HCBS being provided prior to the admission as 7.3 percent (Gold, 2007) for NYS, just one example of unnecessary institutionalization. Personal care services, like all Medicaid HCBS, may receive more scrutiny as States face potential budget deficits, yet bypassing existing HCBS programs and admitting directly to a higher cost institutional setting is not a feasible expenditure of public funds, compliant with Olmstead, nor in anyone's interest save the for-profit nursing home industry.

In recent years, economic and demographic forces have driven the costs of Medicaid programs to the point that states are scarcely able to pay their share of costs, and have been placed in a situation where difficult program reductions have been proposed (Smith & Moody, 2005). The current situation of increased need, combined with limited resources, elevates the issue of future provision of Medicaid HCBS to one of great importance. Continued research and documentation has the potential to highlight those areas of highest priority, along with those programs that exhibit better practices. This may ensure that programs that provide Medicaid HCBS, and specifically personal care, remain available, sustainable and beneficial in the future.

From 2000 to 2007, home health care has been cut by 25 percent, from \$14 billion to \$10.5 billion. It is cut further in the Bush administration's proposed fiscal year 2008 budget, which calls for an "inflation freeze" that would slash \$410 million in Medicare funding fiscal 2008 and \$9.68 billion over five years (Koch & Weiner, 2007). According to Koch and Weiner (2007) in their strong opinion position on the continued support for homecare options, New York would be one of the five states hit hardest, losing

\$567 million in aid for home health care during that period (Koch & Weiner, 2007) making this an important priority for New York.

THEORETICAL FRAMEWORK OVERVIEW

Social phenomena can be viewed as the behavior of individuals, of organizations, or of systems of organizations (Scott, 2003). Understanding of public policy, government, decision-making, and social change is most usefully approached from an organizational perspective (Scott, 2005). Accordingly, this section discusses the organizational context for the study and looks at the issue of PCS delivery from an organizational perspective as the most useful conceptual model.

An understanding of organizations – how they form, operate, change, survive, and die – is essential to the study of public policy, government, decision-making, social change, and leadership (Scott, 2003). Organizations, according to Scott (2003) are important objects of study and concern for many reasons - one being that they are vital mechanisms for pursuing collective goals in modern societies. Organizational theory enables one to identify, understand, and apply concepts to contemporary organizational and policy challenges in a variety of arenas. Similarly, with a basic understanding of the dimensions of organization theory one can pay particular attention to how political, cultural, and social policy trends take shape.

Diverse levels of analysis apply when researching organizations. The level of analysis is determined by the nature of the dependent variable - that is, by whether the phenomenon to be explained is the behavior of individuals, of organizations, or of systems of organizations (Scott, 2003). The three basic levels outlined by Scott (2003) are: The *social psychological* level, focusing on the behavior of individuals; The *organizational structure* level, focusing on the structural features or processes that characterize organizations; and, The *ecological* level, focusing on the characteristics or

actions of the organization viewed as a collective entity operating in a larger system of relations.

Much of the history of the development of organization studies during the last quarter of the twentieth century to the present reflects a growing recognition of the many and diverse ways in which the environment constitutes, influences, and penetrates organizations (Scott, 2004). Applying ideas from contemporary schools of thought about organizations to the provision of publicly funded personal care services at the state level is primarily an investigation of organizational structure and processes, with some overlap into both the social psychological and the ecological level. Utilizing an organizational theoretical approach as a conceptual framework for studies on a public policy program analyzed at any of these three levels provides the researcher a broader (macro) view of the multiple players and processes involved in society's collective goal of serving the need for those who require assistance with PCS that they cannot afford to purchase on their own.

Organizational Theory Development

Organizations emerged as a recognized field of social scientific study during the 1950s (Scott, 2004). Scholars and practitioners who comprise the field of organizational studies come from sociology, political science, economics, psychology, business, policy, and education among other areas. During this formative period beginning in the 1950s and continuing into the 1980s, sociologists pursued a variety of topics, but their most distinctive and consistent focus was on the determinants of organization structure (Scott, 2004). Early writings about organizations as a formal field of study feature rational models of organizational behavior (Taylor, 1916; Fayol, 1916; Weber, 1946). The main

dimensions of these early models stressed reliability and productivity, addressing the motions of workers and packaging of tasks into jobs (Taylor, 1916), or devising principles for subdividing and coordinating complex work systems (Fayol, 1916). Weber (1946) continued the rational argument of organizations as dominated by rational, instrumental behavior.

Barnard (1938) and Selznick (1948) were among the first scholars to focus attention on the organization as the unit of interest (Scott, 2004). A noted organizational sociologist himself, Scott (2004) describes the evolution of organizations, through the work of these two scholars, as not only technical production systems (Taylor, 1916; Fayol, 1916), but also as adaptive social systems attempting to survive in the environment.

Environments continued to define the direction of organizational studies as the field grew. The entry of *open systems models* came about as a result of an interdisciplinary effort to focus on commonalities in elements and processes across varied systems, from cell biology to the solar system, impacting organizational studies as well (Scott, 2004). Before open system ideas, organizational scholars had concentrated on actors (workers, work groups, managers) and processes (motivation, cohesion, control) within organizations (Scott, 2004). Attention was now being paid to the environment in which organizations existed (Lawrence & Lorsh, 1967).

Major theoretical perspectives emerged following the introduction of open system models that have contributed to the study of organizations. They include: contingency theory, resource dependency, organizational ecology, general systems theory, institutional theory, network approaches, strategic management, economic perspectives,

and archetype theory. Each is briefly presented here, with a broader emphasis given to institutional theory.

Contingency theory is an approach that recognized that, although all organizations are dependent on their environment for resources and technical information, these environments vary in complexity and uncertainty (Woodward, 1958; Lawrence & Lorsch, 1967). Contingency theory asserts that organizations whose structures are best adapted to their specific environments are expected to perform best (Scott, 2004) and, although an early approach to studying organizations, this theory remains influential (Donaldson, 2001).

Resource dependency theory stresses the benefits of adaptation to the environment, including political as well as economic systems. Developed by the work of Pfeffer and Salancik (1978), this framework recognizes that organizations must exchange resources to survive, but that such exchanges, if imbalanced, give rise to power differences. Resource dependency scholars stress that managers must take steps to manage not only their structures but also their environments, reducing dependencies and seeking adequate power advantages (Scott, 2004).

General systems theory, a broad intellectual movement affecting many sciences, invaded the domain of organization studies during the 1960s and transformed it by calling attention to the pervasive importance of the broader context, the environment, within which organizations operate (Scott et al., 2000). This focus on the importance of organizational activities expanded from the immediate environment to encompass broader and more comprehensive phenomena affecting organizations and the greater aspects of the environment in which they exist. *Organizational ecology* examines factors

affecting the founding, growth, and eventual decline of aggregates of organization, or *organizational populations*.

Philip Selznick, a student of bureaucracy at Columbia, developed his own natural systems model, which was refurbished and elaborated on to constitute an influential approach to the analysis of organizations known as *Institutional Theory* (Scott, 2003). The distinguishing characteristic of formal organizations, according to Selznick (1948), is that they are rationally ordered instruments designed to attain goals, and can “never succeed in conquering the non-rational dimensions of organizational behavior”. The sources of these non-rational features are: (1) individuals, who participate in the organization as “wholes” rather than acting merely in terms of their formal roles; and (2) organizational structures that include the formal aspects but also the complex informal systems that link participants with one another. Organizational procedures become valued as ends in themselves (Selznick, 1948).

Although Selznick’s early work emphasized the constraints imposed by individual and environmental commitments, his later work increasingly recognized that this same process could be a source of strength and change (Scott, 2003) where, in some cases, participants came to share a common set of commitments and a unity of purpose. Selznick, 1948, argued that the most significant aspect of institutionalization entailed the process by which structures or activities became “infused with value beyond the technical requirements at hand”.

New Institutionalism in organizational analysis entered the field of organizational studies in 1977 with the publication of seminal papers by Meyer and Rowan (1977), works about formal structure in organized institutionalism as “myth and ceremony”

(Meyer & Rowan, 1977) that set out many of the central components of neo-institutional thought (Powell & DiMaggio, 1991). This *New Institutional* perspective emphasizes the ways in which action is structured, and order made possible, by shared systems of rules that both constrain the inclination and capacity of actors to optimize, as well as privilege some groups whose interests are secured by prevailing rewards and sanctions (Powell & DiMaggio, 1991).

The differences between the old and new institutionalisms are made evident in: analytic focus; approach to the environment; views of conflict and change; and images of individual action, and are considerable (Powell and DiMaggio, 1991). New Institutionalism takes into account the cognitive turn in social theory at the time (Parsons, 1951; Garfinkel, 1967), and emerged with a principal goal of addressing practical action around issues of change, power, and efficiency (Powell & DiMaggio, 1991). When organizational change does occur, it is likely to be episodic and dramatic (Powell and DiMaggio, 1991), responding to institutional change at the macro-level, rather than incremental and smooth. Powell and DiMaggio (1991:11) assert that, “institutionalized arrangements are reproduced because individuals often cannot even conceive of appropriate alternatives (or because they regard as unrealistic the alternatives they can imagine)”.

While each of these organizational perspectives have been utilized in empirical studies on various health care organizations in the US (Flood & Fennel, 1995), it is the evolution of institutional theory that focuses on, and offers, a conceptualization of what occurs as a whole. From the 1980s to present, sociologists have led the way in examining the structural characteristics of collections of interdependent organizations (the structure

of organizational fields and networks). By offering such a broad view, Institutional Theory encompasses each of the other organizational perspectives outlined above and, by doing so, allows one to focus in on any one sector in a selected environment without losing perspective of the forces that affect the whole in the process.

Another aspect of analyzing processes of change in organizations not discussed above is the concept of *archetype theory*. Greenwood and Hinings (1993) built a case asserting that organizations conform to certain underlying patterns or *archetypes* that provide templates for organizing. Incremental change involves the development of organizational structures and systems within the constraints imposed by the existing archetype; while discontinuous change (transformation) involves the addition of a second archetype or the substitution of one archetype for another (Scott et al., 2000). According to Scott and colleagues, discontinuous change rarely occurs within the boundaries of existing organizations. Since it requires the substitution of one template for another, or the combining of templates, it is more likely to occur by selection than by adaptation, leading to the creation of a new organization population.

In a more recent critique, Kirkpatrick and Ackroyd (2003) argue the validity of the archetype theory and offer an alternative. A key weakness of the archetype theory, they argue, stems from the continued legacy of functionalism in this approach and the limited role given to human agency. A further problem they articulate is the uncritical generalization of assumptions about professional organization and change, especially in the context of public services. These difficulties, as suggested by Kirkpatrick and Ackroyd (2003) bring into question the usefulness of archetype theory as a general model for understanding change, especially changes occurring in the public services field. Their

alternative combines recent advances in social theory dealing with the relationship between agency and structure, with ideas from the sociology of professions (Kirkpatrick & Ackroyd, 2003).

While contemporary theorists argue the finer points of archetype theory's ability to document agency in the rapidly changing healthcare field, Kitchener and Harrington (2004) demonstrate the applicability of archetype analysis to the social policy arena of PCS (as a subset of HCBS) in a study on the US LTC field: a dialectic analysis of institutional dynamics.

Applicability of Organizational Theory to the Social Policy Arena of PCS

Kitchener and Harrington (2004) present an historical account of institutional dynamics being played out on the LTC sector between two forces operating within it. By documenting the purposive action (agency) of these two major archetypes (HCBS vs. the nursing home industry) playing on the same field, this study demonstrates the benefit of utilizing Institutional Theory to understand these two opposing forces that, theoretically, profess to have the same endgame focused on the delivery of positive healthcare outcomes. Using archetype theory and an institutional perspective, this study offers viewers a box seat for a dynamic play- by- play account of the historical dialectic tensions involving not only the two major "teams" (HCBS vs. nursing home industry), but the individual players (nursing home and home care providers, government, and consumers) that make up each.

The analysis provided by Kitchener and Harrington (2004) emphasizes that organizations are open systems, strongly influenced by, and influencing, their environments. There appears to be strong evidence from this study that demonstrates

what Powell and DiMaggio (1991) assert in stating that, “efforts to incorporate power into institutional arguments begin with two simple observations: (1) actors in key institutions realize considerable gains from the maintenance of those institutions; and, (2) when organization fields are unstable and established practices ill formed, successful collective action often depends upon defining and elaborating widely accepted rules of the game. Consequently, the acquisition and maintenance of power within organization fields requires that dominant organizations continually enact strategies of control, most notably through either the socialization of newcomers into a shared worldview or via the support of the state and its judicial arm (Powell & DiMaggio, 1991:31).

North (1990), an economic historian, concurs, viewing institutions as systems of rules or as governance systems. He argues that:

“[Institutions] are perfectly analogous to the rules of the game in a competitive team sport. That is, they consist of formal written rules as well as typically unwritten codes of conduct that underlie and supplement formal rules. The rules and informal codes are sometimes violated and punishments are enacted. Therefore, an essential part of the function of institutions is the costliness of ascertaining violations and the severity of punishment.” (North, 1990:4).”

Another study that demonstrates the benefits of utilizing organizational approaches to gain a better understanding of the health care field is by Flood and Fennel (1995). These authors reviewed various theoretical perspectives on organizational change through different “lenses” that can be applied to medical organizations. Discussing multiple organizational perspectives as filters (alternative lenses) influencing our observations (research), and mirrors of the shifting dynamics of delivery system reform (policy), the authors conclude with an examination of how such theories provide useful insights into a rapidly changing healthcare system.

In addition, a study of institutional change and healthcare organizations demonstrates the applicability of organizational theory to this area of study. Scott, Ruef, Mendel, and Caronna (2000) articulate several concepts regarding how existing organization do new things, or old things in new ways (adaptation). The authors look at changes that occur because existing organizations are replaced by new types of organizations (ecological change). Scott et al. (2000) explored how hospitals adapt in a variety of ways to changes in their environments: adding services, forming alliances, joining systems, and merging. The authors assert that a differentiation is made between *incremental* and *discontinuous* change (Scott et al., 2000), finding that much change occurs gradually and almost imperceptibly as organizational forms add and subtract personnel, subunits, and services or products. Scott et al. (2000) present data that supports the hypothesis that change sometimes occurs abruptly, and in such a manner that the situation is greatly altered (transformed).

The findings in these articles, and book, above have built a case for the applicability of using organizational approaches to study the social policy arena of PCS. Institutional theory, like organizational ecology and resource dependence, developed quite rapidly during the mid-1970s and up to the present (Scott, 2003). The dimensions of the organizational environment from an Institutional perspective are outlined below.

-Insert Table 5 here - (see Appendix A: A Generic Conceptual Framework for Organizational Field Analysis of the Personal Care Field)

Dimensions of Organizational Environments from an Institutional Perspective

Scott et al. (2000) outlines three levels at which organizations may be studied and include: (1) the organization set, (2) the organizational population, and (3) the organizational field.

The organization set is defined as encompassing a given organization of interest, the focal organization, together with its relations to other organizations that are critical to its functioning and survival (Scott et al., 2000). Organizational perspectives applicable at this level include contingency theory (Lawrence & Lorsh, 1967), related economic approaches which focus on transaction costs, and those that are governed by power struggles within or between organizations, such as resource dependency (Pfeffer and Salancik, 1978), and the strategic management approaches (Mintzberg, 1983).

The organization populations are specific time-and-space instances of organizational forms. An organizational population consists of the set of organizations with a particular form within a (bounded) social system. The population ecology approach is applicable at this level, where the interdependence of several related populations or the erosion of the boundaries of existing populations may be observed (Scott et al., 2000).

The organization field level of analysis is a most useful perspective as it encompasses, as defined by DiMaggio and Powell (1983): “those organizations that, in the aggregate, constitute a recognized area of institutional life: key suppliers, resource and product consumers, regulatory agencies, and other organizations that produce similar services on products. So defined, *fields* incorporate both organization sets (individual organizations), and their exchange partners and competitors, and organization populations.

The environmental level is defined as including structures and processes, which, though not themselves the subject of explanation, are expected to shape or influence that subject (Scott et al., 2000). Two broad categories of environmental variables are

distinguished in this conceptual framework: the material-resource environment and the institutional environment. Theories relevant to the material-resource environment are those of organizational ecology and economics (Scott et al., 2000), while institutional theory assists in conceptualizing and understanding the institutional environment.

Scott et al. (2000) presents a generic conceptual framework for organizational field analysis (see Appendix A). The focal field of study (for this paper - investigating the development of publicly funded PCS in New York State) contains within its open system borders: logics (e.g. professional dominance, federal involvement, market management); governance systems (e.g. licensing, certification); and, actors (the individual and collective actors) involved in the PCS sector. The Material-Resource Environment and Institutional Environment are clarified below.

Material-Resource Environments

All organizations require resources from the environment, and all organizations are engaged in production processes by which inputs are transferred into outputs through the application of energy, information, and skills (Scott et al., 2000). The material-resource environment is that facet of the environment most directly relevant to viewing the organization as a production system depending on, and transforming, scarce resources (Scott et al., 2000). The Material-Resource (see Appendix A) environment is conceptualized as being comprised of four sets of factors: (1) demand-side factors, (2) supply-side factors, (3) technologies employed by field participants, and (4) the structure of the industry as it affects the flow of resources among organizations. These factors are outlined in their relation to PCS.

Economic Perspectives offer theoretical approaches that simplify and allow the theorist to zero in on one aspect of a phenomenon (Perrow, 1986). Classic economists focus on macroeconomic behavior at the level of markets and economies, whereas neoclassical economists remain committed to the individual as the unit of analysis. Newer economic models, such as transaction cost economics deal with efficiency, and assert that efficiency is the main, and only systematic factor, responsible for organizational change (Williamson, 1981).

Supply & Demand Factors

There are multiple supply and demand factors involved in publicly funded PCS, the workforce being primary to the supply of services. The workforce providing non-institutional personal assistance and home health services tripled between 1984 and 2004, according to US survey data, growing at a much faster rate than the population needing such services (Kaye, Chapman, Newcomer, & Harrington, 2006). This study on the trends in supply and demand of the personal work force (Kaye et al., 2006) also reports that low wage levels for personal workers, which have fallen behind those of comparable occupations; scarce health benefits; and high job turnover rates highlight the need for greater attention to ensuring a stable and well-trained workforce to meet growing demand.

Supply-side factors are those having to do with need and supply of services. PCS are dependent on an available workforce to provide care. The structure of factors affecting the supply of an available workforce depends on numerous factors that include: availability of the workforce; cost of services; access of consumers to available workforce; and understanding of their options to choose from a variety of options. PCS paid for by Medicaid have, until recently, been offered predominantly through an agency

model, with the locus of control of PCS for the consumer with the agency, with workers employed through this formal agency structure. Supply and demand-side factors are being shifted dramatically with the influence of consumer-direction.

Demand-side factors. In addition to the federal Olmstead ruling, and subsequent litigation demanding services to consumers (Kitchener et al., 2005), consumer-directed care (also called self-direction) offers persons with chronic illnesses and disabilities an ability to make decisions about the services they want and how they wish to receive them. States affect consumers' choices, especially when the cost of PCS is by a third-party payer.

While people who pay for HCBS with their own funds have always been able to direct their own services, it is only over the past decade that consumer-directed services have proliferated in public programs. Older people's preferences were voiced clearly in a 1997 survey conducted for the American Association of Retired Persons (AARP) that found that more than three-fourths (76 percent) of people age 50 and older would prefer to manage their own home care services rather than received services managed by an agency (Kassner, 2006). A subsequent survey, in 2002, of people with disabilities age 50 and older found that only 15 percent preferred agency-directed services (Kassner, 2006).

The demand for PCS is growing for older persons and younger disabled, as is the demand for more control by these consumers as to how those services should be delivered. Continued growth in the personal services workforce will be necessary to meet the expected increase in demand according to Kaye et al. (2006) who, in addition, point out that an unstable workforce can compromise both access to services, and the quality of services received.

Technologies

Organizational theories define the concept of technology broadly to include not only the hardware but also the skills and knowledge utilized by field participants to transform inputs into desired outputs. Both providers, and consumers may utilize assistive technologies. While PCS refer to formal assistive services provided by others, personal assistive services (PAS) refer to the technologies that provide greater independence to consumers. PAS (which may include PCS), along with assistive technology such as wheelchairs, text readers, and hearing aides, help people with chronic illnesses and disabilities to participate in activities at home, at work, and in the community (PAS Center, 2007).

Technology has become an important part of state home and community-based service systems to support the assessment and care planning process. One reason being, that the assessment process has always been a paper intensive one. Due to increased assistive technologies, programs are now available that: prepare, document, and print service plans; authorize service hours and set payment rates; and enable program administrators to track and compare consumers across care settings and time (Mollica & Gillespie, 2003).

Industry/Market Structure

Industry/Market Structure encompasses the structures under which provision of PCS is delivered in the US. Both HCBS and institutional care facilities such as nursing homes are included, as are: assisted living housing, and emerging hybrids of both that are being created through innovative alternatives to nursing homes such as the Eden Alternative (Dentzer, 2002). Kitchener and Harrington (2004) document the industry

market forces at play in the LTC sector over the last quarter century, describing the competitive field at play between the competing archetypes. As home and community-based services received greater government funding, a larger market was constructed for corporate exploitation (Kitchener & Harrington, 2004) and, despite mounting evidence of consumer preference for home and community-based services, the LTC field is still dominated by nursing homes that consume the majority of government LTC expenditures.

Institutional Environments

The institutional environment is composed of regulative, normative, and cultural-cognitive structures that operate to provide coherence, meaning and stability to a field (Scott, 1995). In the last half a century there have been dramatic changes in the rules governing healthcare systems and in our beliefs regarding medical care and its delivery (Scott et al., 2004). Since the concept of institutionalization is not definitively linked to a distinctive process, analysts begin to theorize more explicitly about the variety of types of process that might cause an organization to change its structure in ways that make it conform to (become isomorphic with) an institutional pattern (Scott, 1987).

Regulative elements include rules, sanctions and surveillance systems; normative, values and internalized expectations regarding appropriate ways of behaving; and cultural-cognitive, shared conceptions concerning the nature of reality and means-ends relations (Scott, 2003). Regulative elements include the laws governing the PCS in each state, with variations in standards.

As noted, early sociologists, such as Weber and Selznick, viewed institutions primarily as *normative* structures providing a moral framework for the conduct of social life, whereas, the most recent version of institutions, the view associated with “the new

institutionalism in organizational analysis” (Powell and DiMaggio, 1991), emphasizes the role of cultural-cognitive processes in social life. Dimaggio and Powell (1983) developed the classification of these processes as coercive, mimetic, and normative processes leading to conformity. The process by which actions are repeated and given similar meaning by self and others is defined as *institutionalization* (Scott, 2003:136).

Analysts such as Van Manen (1973) introduced ideas concerning the construction of social reality at the micro level, working in the symbolic interactionist and ethno-methodological traditions (Scott, 2003). Analysts such as Meyer and Rowan (1977), however, emphasize the importance of cultural rules in wider institutional environments (Scott, 2003). The key theme stressed by Meyer and Rowan in Scott’s (2003) explanation of the conceptions of environments is that organizations receive support and legitimacy to the extent that they conform to contemporary norms, as determined by professional and scientific authorities, concerning the “appropriate” way to organize. These beliefs are so powerful that organizations that conform to them receive public support and confidence even in situations where no specific technical advantages are obtained (Scott, 2003:137); As Scott writes, “Some organizations in each type of environment achieve more by the exercise of monopoly or political power than by conforming to institutional demands or by effective technical performance.”

DiMaggio and Powell (1983) introduced the processes (pressures) governing this *new* institutional environment as coercive, normative, and mimetic. Kitchener and Harrington’s (2004) example of these type of processes in the current institutional environment of PCS is demonstrated in research findings documenting that the role of political agency is underscored in national studies which demonstrate significant

relationships between Democratic state governorship and higher rates of spending on HCBS, and between Republican state governors and stringent Medicaid HCBS policies (Kitchener, Beynon, & Harrington, 2004).

Personal Care Services Field (the Focal Field)

Three components in the focal field (PCS field here) that are of importance include: (1) logics, (2) actors, and (3) governance systems (Scott, 2004). (Appendix B).

Logics

Logics are sets of “material practices and symbolic constructions which constitute (a field’s) organizing principles and which are available to organizations and individuals to elaborate” (Friedland & Alford, 1991:248). These logics are the cognitive maps, the belief systems carried by participants in the field to guide and give meaning to their activities (Scott et al., 2000).

Actors

Institutional actors function both as carriers and creators of institutional logics. The institutional environment contains a variety of such actors, either individuals or organizations. Actors participate in the material-resource environment, as consumers or suppliers of PCS, but also participate in the institutional environment, possessing institutionally defined identities, capacities, rights, and obligations. Actors in organizational field analysis of PCS include consumers and their advocates, service providers, regulators, and policy makers.

Governance systems

Governance systems are those “arrangements, which support the regularized control, whether by regimes created by mutual agreement, by legitimate hierarchical authority, or by non-legitimate coercive means, of the actions of one set of actors by another,” (Scott, Mendel, and Pollack, forthcoming). Each societal sector or field is characterized by a somewhat distinctive governance system, composed of some combination of public and private actors employing both regulatory and normative controls over the activities conducted within that field.

The institutional framework for organizational analysis discussed in this paper does offer a theoretical tool to: identify the components of the field, identify the actors involved; and describe the systems that govern them. Scott (2006) sums up his own typologies, devised for *Organizations* (rational, natural, and open systems); and for his book, *Institutions and Organizations* (regulative, normative, and cultural-cognitive elements), as his most creative contributions. He states,

“They provide conceptual frameworks within which it is possible to show not only that multiple different perspectives on the subject exist, but to assess what the differences are, how and why they are different, and what difference it makes on one’s view of the subject. The identification of these multiple conceptual frameworks does not resolve their difference, but opens them up for review, evaluation and comparison.” (Scott, 2006:890).

What this framework does not offer, a blind spot if you will, is a means to understand the forces at play (agency) in larger movements that attempt to overthrow the institutionalized holders of power. Social Movement Theory may offer this.

Conclusion

In conclusion, the institutional environment of a Medicaid PCS program encompasses the cultural belief systems, normative frameworks, and regulatory systems that provide meaning and stability to this social service sector. The conceptual framework developed by Scott et al., (2000) (Appendix A), is a useful and feasible tool to assess and analyze better practices in the planning, facilitation and oversight of a PCS program. Healthcare analysis at the organization level examines the social structures created by individuals to support collaborative pursuit of goals. Institutional is one organizational approach that offers an understanding of the profound changes, or inertia, in organizations (PCS programs) viewed from this theoretical stance. The most influential applications of institutional ideas to the analysis of organizations operate at this macro level.

DiMaggio (1986: 337) asserted twenty-one years ago: “The organization field has emerged as a critical unit bridging the organizational and the societal levels in the study of social and community change”. There appears to be strong evidence that this remains so, as a social movement of consumers demand for increased services through a more balanced allocation of Medicaid funding for PCS in the US. As organizations become more movement-like (politicized), and movements borrow strategies from organizations (Davis et. al., 2005), identifying the logics that are influencing change in PCS programs will demonstrate the value of this interchange.

CHAPTER THREE

Research Design and Methods

A case study format was utilized for researching developments in the NYS Medicaid PCS program. Case study methodology is appropriate when “how” and “why” questions are being posed and, as in this study, when the investigator has little control over events, and when the object of attention is a contemporary phenomenon in a real-life context and occurring in real time (Yin, 2003). The study incorporated both qualitative data, such as key stakeholders’ expressed beliefs regarding LTC in NY, and quantitative data, such as demographic and financial data (participants and expenditures). The qualitative research methods selected for this case study allowed holistic and meaningful characteristics of real-life events such as organizational and managerial processes to be documented and analyzed.

As noted in Chapter 1, this study had three specific aims:

Aim 1:

To describe the NYS PCS program in terms of its governance, organization, and management structure, including the extent of its consolidation, integration, and decentralization.

Aim 2:

To examine trends in the NYS PCS program, specifically in the participants and expenditures, from 1999-2005.

Aim 3:

To examine how competing logics of key stakeholders are influencing change and inertia in the NYS PCS program.

Data Collection

Four data sources have been used: 1) documentary research; 2) secondary data analysis; 3) interviews with state and local officials, and 4) interviews with representatives of other key stakeholder groups. For the documentary research, this case study included electronic and archival print sources, available from NY State and national public domain sites, and secondary data such as the compilations available from the UCSF PCS Center. Documentary evidence included, for example, organizational charts and contracts between the state and provider agencies.

For the secondary data analysis, quantitative data were obtained from the UCSF PCS Center that tracked trends in the PCS program in NYS from 1999-2005 (see Aim 2 findings) and related them to other PCS program activity in the US.

Interviews with state and local officials and with selected stakeholder groups were the primary sources of information. Twenty-one face-to-face interviews, and one telephone interview, were conducted with three primary groups of study participants (see Table X): 1) state and city officials; 2) directors of agencies that provide personal care services; and 3) representatives from other key stakeholder groups such as a predominant labor union in NYC, consumer advocacy organizations, and health institutes involved in workforce issues and policy research on LTC in NYS.

Interview Sample

Selected NYS and NYC officials, directors of provider agencies, consumer groups, union officials, and other key stakeholders in NY, were recruited to address the aims of the study. The study initially proposed that twenty to twenty-five interviews would be conducted. This sampling number estimation was put forth to answer the research

focused on what the developments in the NYS Medicaid PCS program are. A sample of twenty to twenty-five was theoretically comprehensive, for this study, to ensure the generalizability of the conceptual analysis (Devers, 1999) by including a diverse range of individuals within each of the four sample categories and in alignment with a purposive sampling approach (Miles & Huberman, 1994). Twenty-two interviews were actually conducted (see Table 6.) to obtain the sample for interview data collection. Study participants were selected initially by conducting Internet searches of the organizational structure and management of the NY PCS program and by key informant referrals to other potential participants.

Table 6. New York State Case Study Participant Interview Groups

Study Participant Groups	NY State and City Officials	Directors of Provider Agencies	Union	Consumer Advocacy and Policy Organizations	Total of Study Participants
Face-to-Face Participant Interviews	8	5	1	7	Total: 21
Telephone Interviews				1	Total: 1
					Total = 22

The study sample included interviews with individuals representing four main groups. They are: 1) State and City officials responsible for the NYS Medicaid PCS program; 2) agencies that provide PCS; and, 3) unions and, 4) advocacy and policy groups in NY representing consumers and the workforce. Potential participant interview subjects were identified via official state office sites, as well as city and agency program directories, and through networking referrals from participating respondents. Potential individuals in the sample were sent an electronic letter of introduction (Appendix B.) explaining the study and detailing the risks, benefits, and option to decline participation.

Site Selection

Because NYC is home to 80 percent of Medicaid PCS participants in NYS and the majority of provider agencies, including the main office for SEIU 1199, the major union involved in collective bargaining for the PCS workforce, it was estimated that face-to-face interviews in Albany and NYC would provide adequate coverage of state officials and other key stakeholder groups to address the aims of this study. Albany is the state capital and center of operations for the NYS Department of Health (DOH) Medicaid officials responsible for the PCS program. Site selection for interviews with targeted participants from these two regions of the state generated rich data that provided ample detail to address the aims of the study.

Informed Consent

Study participants were advised that their participation was entirely voluntary and that they had the option to not participate. Participants were informed that their names would not be revealed nor linked to information they provided. Only generally available program information or aggregate data was requested. No patient data was collected.

Risks to respondents in the twenty-one personal interviews and one telephone interview were minimal because they were not asked about individual program recipients, only about the organization of the NY PCS program. Although it was anticipated that the tone of the interviews would be neutral and disinterested, there was a possibility that some participants might perceive some of the discussion topics or interview questions as confrontational. To allay possible difficulty in this regard, three pertinent points were explained to each interviewee prior to the interview: 1) participation throughout the interview was voluntary; 2) participants could decline to answer any question or discuss

any topic raised; and, 3) participants could end the interview at any time. In addition, it was explained to subjects that confidentiality would be strictly maintained. The names of interviewees were kept separate from data they provided. Individual participants are not identified here nor will they be identified in any talks, papers, or further reports. Results from interviews have been presented anonymously as in, “one state official said”. All field notes, recordings of interviews, and transcriptions, are kept locked and separate from the respondent identifiers. It was convenient for the interviewer to make a digital recording of most of the interviews conducted. In each case, an explicit request was made before the interview began and the interview subject was given the opportunity to decline to be recorded if he or she desired, though none did.

Interview Parameters

To examine developments in the NYS Medicaid PCS program, data analysis focused on three key concepts: governance, actors, and logics. Analysis involved examining, describing, and reporting on the data gathered from participant interviews (see Table 6 above) utilizing the study instrument questionnaires (Appendices C., D., & E.) and from documents gathered on LTC and the PCS program for NY (listed in Appendix F.) and from papers cited and referenced in this report.

Participant interviews were guided by three separate semi-structured questionnaire instruments designed to elicit data from four distinct, yet related, groups of participants: 1) NYS and NYC officials (Appendix C.); 2) agencies that provide PCS (Appendix D.); 3) unions (Appendix E.); and 4) consumer advocacy groups (Appendix E.).

The questionnaire instruments were designed to provide a preliminary list of data

codes before the actual data collection began, as recommended by Miles and Huberman (1994) and Maxwell (2005), and to elicit information organized into three sections: agency; clients; and, PCS organizations /workforce. Responses to pertinent questions within each of these three sections provided rich data for ongoing comparative analysis on the governance, actors, and logics, in the development of the NY PCS program. The initial questions sought for data collection and coding purposes put the investigator in a focused mode for addressing the primary aims of the study and staying on course throughout the interview process to achieve them. The specific aims for this study are repeated below to articulate the analytic process involved in achieving them.

Data Collection Strategy

Interviews with a balance of state and city officials, directors of PCS provider agencies, and other key stakeholder groups (unions and consumer advocacy organizations) provided the opportunity to investigate emergent themes and patterns as data collection progressed. For pragmatic travel reasons only, the planned interviews were set up to first meet with state officials, followed by other participants in the Albany region, and then proceed to NYC for interviews there. It was important to maximize the time spent to elicit logics using the semi-structured study questionnaires, leaving enough time in between interviews for the investigator to organize and reflect on field notes prior to conducting subsequent interviews. As there were anywhere from two to four interviews scheduled on any given day in the 10-day data collection period, it was vital to prepare for each interview to be as objective as possible. Also, because a different study questionnaire was used for each participant it was important for the investigator to be prepared in advance of each interview by using the correct study question guide to elicit

information about logics regarding the program. This was accomplished by doing a short recap of the investigator's study at the beginning of each contact, consistent with the letter of introduction that went to each study participant, followed by the opportunity for each participant to ask any questions prior to the formal interview beginning. It was after this short introduction that a request was made, with the participant's verbal permission, to digitally record the interview.

This introductory preparation was rewarded in a number of ways. First, recapping the aims of the study in person with each participant as a way of introduction assisted the investigator to relax and frame the process to ensue. Second, it also allowed an atmosphere of inquiry and non-judgment to be present, and for consistent, unbiased patterns to be established with each interview. Third, it also appeared to be effective in allowing the study participant to trust the investigator and the process, for each participant agreed to allow a digitalized recording of the interview session. And finally, while the investigator committed to taking only one-hour of each participant's time as a professional courtesy for their participation, on numerous occasions, participants led the interview to extend beyond the hour even when the investigator strove to stick to the one-hour limit.

The majority of interviewees gave every indication that they appreciated the opportunity to express their views on the subjects raised. The non-confrontational, inquisitive style of the investigator, coupled with their sharing of professional experience supervising a HCBS program in the past, appeared to establish a mutual sense of "knowing" that allowed the participants to delve deeply into their beliefs about the PCS program in NYS without needing to explain the program to the investigator. Most

interviews were conducted in the participant's office or a conference room reserved for the investigator's visit. The unobtrusive recording device suited the objective of digitally documenting the data without making the participant uncomfortable, according to feedback from participants.

Transcribing the interviews allowed the storage of rich, qualitative data. It also allowed the investigator to relax, engage in natural conversation and take field notes during the interview without the reactivity associated with rushed stenography. In addition, the recordings and transcripts provided feedback to the investigator regarding self-conduct during the study interviews. Subsequent email messages from study participants wishing to share further information on the NYS PCS program or thoughts post-interview confirmed the positive, open and non-judgmental atmosphere created by the investigator.

Data Analytical Strategies

Triangulation, or using more than one method to verify and validate results (Yin, 2003), such as using a mixed method approach that includes qualitative and quantitative data, ensured the achievement of all three aims of the study. Triangulation is but one tool to enhance the rigor of any qualitative study. These strategies and others are explained in detail in a series of articles, *Qualitative Methods in Health Services Research (HSR)*, a special supplement to HSR including articles from an invitational conference in December 1998 (Devers, 1999; Patton, 1999; Yin; 1999) that provided guidance for the strategies used in this study (see Table 7 below).

Health services researchers establish "trustworthiness" of findings from studies using qualitative methods when the work is assessed in terms of its credibility,

transferability, dependability, and confirmability (Lincoln and Guba, 1985). Credibility is “the truth” as viewed through the eyes of those being interviewed and within the context of the research being carried out (Devers, 1999). Dependability is the extent to which the research would produce similar or consistent findings if carried out as described, including taking into account any factors that may have affected the research results (Devers, 1999). Confirmability comes directly from subjects and research context, rather than the researcher’s biases, motivations, or perspectives. Transferability is the extent to which findings can be transferred to other settings (Devers, 1999). According to Devers (1999) the role of the researcher in relation to transferability is to identify key aspects of the context from which the findings emerge and the extent to which they may be applicable to other contexts.

There are three distinct but related inquiry concerns in relation to credibility and qualitative research according to Patton (1999). These are: 1) rigorous techniques and methods for gathering and analyzing qualitative data, including attention to validity, reliability, and triangulation; 2) the credibility, competence, and perceived trustworthiness of the qualitative researcher; and 3) the philosophical belief in the value of qualitative inquiry. That is, a fundamental appreciation of naturalistic inquiry, qualitative methods, inductive analysis, purposeful sampling, and holistic thinking.

Patton, along with other noted health service researchers concerned with enhancing the quality and credibility of qualitative health services research, gathered for an invitational conference in Maryland in December 1998. The conference, co-sponsored by the Agency for Health Care Policy and Research and the Robert Wood Johnson Foundation, also resulted in the publication of a special supplement to the Health

Services Research (HSR) journal in December 1999. The special supplement to HSR drew attention to the growing role played by qualitative methods in health services research and provides the basis for qualitative research methods in developing a science of “evidence-based implementation” (Shortell, 1998). The series of eight published peer-reviewed articles in the special supplement of HSR (1999) offer a valuable resource and support for qualitative methodology for this study.

Yin (2003) argues that no matter what specific analytic strategy or techniques are chosen, four principles underlie high quality analysis of qualitative data. These are: 1) all the evidence is attended to; 2) all rival interpretations are addressed; 3) the analysis identifies and addresses the most significant aspect of the case study; and, 4) the investigator uses his or her own prior expert knowledge (Yin, 2003). These principles governed the course of the study, including data collection from each study participant group, the data analysis, and the reporting. Other health services researchers experienced in qualitative research methods vetted the results. All efforts were made to match the methods appropriately to the aims and issues outlined above in order to produce a high-quality document that will be useful to researchers and policy-makers interested in LTC policy and programs.

Table 7. Strategies Enhancing the Rigor of this Case Study

Criteria	Strategies Used
Credibility/Internal Validity	<p>Triangulation: Multiple data sources used for both documents and participant interviews with various stakeholder views expressed.</p> <p>Search for Disconfirming Evidence: All data addressed, including contrary views or those not fitting the majority pattern.</p> <p>Subject Review: Member checking employed by ongoing dialogue with study participants to solicit credibility of interpretations and findings.</p>

Transferability/ External Validity	The context to which findings can be transferred to other settings. Identifying key aspects of the context from which the findings emerge and the extent to which they may be applicable to other contexts.
Dependability/ Reliability	Data Archiving/Creating an Audit Trail: Researcher has ensured the completeness and accuracy of documents (in appendices) and participant interviews (transcriptions from recorded interviews retained and safeguarded). Coding schemes explicit in study instrument questionnaires so that findings, interpretations and conclusions are supported. Skeptical Peer Review: External check on methods, meanings and interpretation of the data provided by academic advisor and dissertation committee members.
Confirm-ability/ Objectivity	Triangulation: see above Skeptical Peer Review/Audit Trail: see above Search for De-confirming Evidence: see above Reflective Journal Keeping by the Investigator: Field notes kept during research process document investigator's acknowledgement of biases and personal experience that might influence the work and how they were managed.

Table adapted from Devers (1999), p. 1172.

Because of their overall value, documents play an explicit role in any data collection in doing case studies (Yin, 2003). That stated, Yin (2003) makes clear, “every document was written for some specific purpose and some specific audience other than those of the case study being done” and the case study investigator should be skeptical of all documentary evidence and its provenance, a warning taken to heart by this investigator.

Data Analysis for Specific Aims

Data analysis focused on three key concepts: governance, actors, and logics, to examine developments in the NY PCS program. These key concepts are depicted in the focal field of study in Appendix A. The influences of the material-resource and institutional environments, also illustrated in Appendix A, were incorporated in the analysis, although they are not the main focus for achieving the stated aims of this study. Analysis involved examining, describing, and reporting on the data gathered from study

instrument questionnaires through interviews with study participants (Appendices C, D, & E.) and from documents gathered on LTC and the PCS program for NY (Appendix F.).

Analysis of Research Aims

Each of the specific aims was analyzed separately.

Aim 1: To describe the NY PCS program in terms of its governance, organization, and management structure, including the extent of its consolidation, integration, and decentralization.

The first aim of the study focused on describing the organizational structure, management system, and goals of LTC in NY and the PCS program. The primary sources of data for this aim came from NY State DOH website accessed documents and from the state and city officials responsible for the NY PCS program. Questions to participants were divided into three categories: 1) agency; 2) client; and, 3) provider agencies and workforce. Questions were further sub-divided by preliminary coding categories to provide ease with the process of analysis.

Data sub-category questions under ‘A. Agency’ included: the organizational structure of LTC in NY; the organizational structure of the PCS program; coordination of LTC and PCS programs; Olmstead planning; federal and state financial support for the PCS program; cost containment measures; quality assurance and monitoring; and litigation and appeals process.

Data sub-category questions under ‘B. Clients’ included: informed choice; eligibility criteria; assessment procedures; services authorization; location of PCS; services offered in the PCS program; and consumer-direction in the PCS program.

Data sub-category questions under ‘C. PCS Provider Agencies and Workforce’ included: contracts and reimbursement; wages and benefits; the labor market;

requirements for PCS workers; and evaluation of the PCS program.

Documents included for data analysis (Appendix F) were organized to compare with responses from study participant interviews and to confirm the data. These documents included organizational charts and location of offices of the state agencies responsible for the PCS program and its quality oversight. Also included were Medicaid regulations, white papers, commissioned reports, news stories and feature articles in newspapers and other mass media, in print or on the Internet, and primary material provided by study participants. Using the collected documents allowed the investigator to corroborate, triangulate, and augment, evidence from other sources, primarily the data from interviews. This process allowed an examination and analysis of developments of the PCS program on a continuum of dimensions articulated in Aim 1, primarily: 1) decentralization vs. centralization; 2) integration vs. fragmentation; and, 3) consolidation vs. dispersion within the state in relation to the PCS program.

The investigator examined and categorized evidence from both documents and interviews. Qualitative analysis of the data was performed using content and thematic techniques that involved searching for recurring words and themes to categorize the data for reporting. Preliminary data codes allowed the investigator to stay focused on the focal field of study during this analysis process in order to analyze and report on key themes in relation to the governance, actors, and logics.

In summary, data analysis for the first aim of the study consisted of examining and categorizing evidence from both documents and interviews. Qualitative analysis of the data was performed using content and thematic techniques that involved searching for recurring words and themes and then categorizing the data collected for reporting on key

themes. Preliminary data codes, established by using an institutional approach for the case study, enabled the investigator to stay focused on the focal field of study, the governance, actors, and logics, to address Aim 1.

Aim 2: To examine trends in the NY PCS program, specifically in the participants and expenditures, from 1999-2005.

To achieve Aim 2, quantitative secondary data collected by the UCSF PCS Center (PCS, 2007) on the NY PCS program was organized and analyzed to report on PCS. The UCSF PCS Center collects program data annually from all state Medicaid PCS programs on key areas that include, primarily, participants and expenditure data. In addition, NYS officials provided data to document growth in the consumer-directed optional program within the PCS program. By analyzing secondary data collected by the PCS Center research team on the NY PCS program from 1999-2005, it was possible to describe trends in the program.

Aim 3: To examine how competing logics of key stakeholders are influencing change and inertia in the NY PCS program.

Two additional interview instrument questionnaires (Appendix D & E) were designed to examine the logics of key stakeholders for the third aim of the study. Questions were arranged into primary data code categories compatible with those used in the study instrument for state and city officials (Appendix C), yet designed to collect logics regarding LTC and the PCS program to allow the investigator to address a broader range of historical, attitudinal, and behavioral issues from directors of PCS provider agencies, union representatives, and consumer advocacy organizations.

Questions were designed to allow a discourse on developments of the NYS PCS program from each of the participants' experience. Making meaning of their experiences,

or *structure of experience* as defined by Van Manen (1990) assisted in analyzing the responses to detect differences, or competing logics. Directors of PCS agencies were not limited to those in NY City. Other key stakeholders interviewed included union officials, directors of consumer advocacy organizations, and directors of institutions that study and support the PCS workforce in NY.

Interviews from these multiple sources of evidence were analyzed together through a triangulation process comparing the interview data from each study participant with those of others to ascertain the validity of findings to interpret and report on competing logics and their influence on change occurring in the development of the PCS program in NYS.

The analysis of the study instrument questionnaires for these participants was organized using the similar key themes (Agency, Clients, PCS Provider Agency, and Workforce) and the same preliminary sub-categories as the instrument used to interview state and local officials. The questions, however, were designed to illicit more on their respective views and less on the organizational structure of the PCS program as those questions posed to the officials responsible for the PCS program in NY.

Analysis of Research Themes

The themes underlying the study are that:

- The NYS PCS program is decentralized and is not well integrated with other LTC programs in the state.
- The level of service and care provided by the NYS PCS program and its sustainability has depended on a broad coalition of stakeholder groups and public support for the program.
- The design of the agency-based NYS PCS program primarily stems from the early unionization of PCS workers and the traditional support for unions in NYC that has resulted in generous worker wages and benefits, and a stable program.

- The pressures from key stakeholders, both individuals and collective disability groups, to expand the consumer-directed delivery of personal care in NYS have challenged the status quo of the NYS PCS's primarily agency-based program, leading to structural and management changes and the expansion of the optional consumer-directed alternative delivery model.

This study draws from institutional theory to analyze how the competing logics (belief systems) of stakeholders have influenced patterns of change and inertia in the development of the NYS PCS program. Interview data, documents, and statistical trend data were collected on the program from 1999-2005. Combining documentary research and secondary data analysis with interview data enabled the investigator to document change and inertia in the NYS Medicaid PCS program over this time period and to analyze hypothesized themes underlying the study. Using an institutional lens to describe change and inertia while examining developments in the program led the investigator to the concept of *imprinting* (Stinchcombe, 1965). Stinchcombe (1965) was one of the first organization theorists to provide evidence that existing organizations are *imprinted* by the environmental period of their founding. By examining how environmental conditions shape organizations, Stinchcombe (1965) hypothesizes that organizations that form effectively tend to become institutionalized, so the basic structure of the organization tends to remain relatively stable, infused with value.

Summary

In summary, for all three aims of the study, findings were not limited to a single source of evidence for data analysis in describing the developments of the NY PCS program. All sources of data were reviewed and analyzed together so that the case study's findings are based on the convergence of information from interviews and document data through a triangulation process and supported by the case study

investigator being acquainted with the procedures associated with using each source of evidence. This is a major strength for data analysis, validity, and reliability for the study.

Miles and Huberman (1994) write of the importance of creating a data analysis plan in qualitative research studies before data collection even begins. This has been achieved for this study in two ways. First, by the preliminary code categories being built into the study questionnaire instruments; and second, by specifically focusing on the collection of data for analysis that concerns three main components in the focal field under study within the NYS PCS Program – the governance systems, actors, and logics. After each study interview was conducted, the resultant data was processed for analysis by converting digital recordings and field notes into the data analysis codes as outlined in the conceptual model for field analysis (Appendix A) and in the study questionnaire instruments (Appendices C, D, & E). This allowed for ongoing data results to take the lead in further data collection. The process of data reduction was used for selecting, focusing, simplifying, and transforming, the data that appear in collected documents (Appendix F), sample interviews, and field notes, from the study to this final written report.

CHAPTER FOUR – FINDINGS

The findings are presented in four sections. The first section presents an overview of the NY health care program while the second, third, and fourth sections each address one of the three aims of the study.

New York Overview

Results on four sets of general NYS characteristics shown to be important within the research literature: (1) socio-demographics, (2) economics, (3) politics, and (4) the state Medicaid program, are presented prior to the research findings of the three aims specified for the study.

NY Socio-Demographic, Economic, and Political Characteristics

In 2004, New York had a population of just over 19 million people, making it the third most populated state in the United States (US) after California and Texas (US Census Bureau, Population Division, 2004) (Table 8). While the population of New York reporting one race alone was predominantly white (68 percent), African Americans comprised the dominant minority population (18 percent), with Latinos a close second (15 percent) followed by Asian (5.5 percent), those reporting some other race (7 percent), and mixed race (3 percent)(US Census Bureau, 2000). Thirty-one percent of the New York population is minority as compared to 24 percent nationally (Table 8).

The proportion of the NY population who were 65+ in 2003 was higher than the national average (Table 8). Also, the proportion of NY residents aged 85 and over were slightly higher than national trends (1.45 percent vs. 1.25 percent nationally (Table 8). In 2003, the percent of NY residents with disabilities resembled national trends, as did those

with difficulty in self-care (Table 8); however, the percent of persons with difficulty in self-care living alone was higher.

Table 8. Socio-Demographic (Need) Characteristics, NY and US

	NY	US
Total Population (2004) ¹	19,227,088	293,655,404
Percent of Persons Age 65+ (2003) ²	12.65%	11.98%
Percent of Persons Age 85+ (2003) ²	1.45%	1.25%
Percent of Population Minority (2003) ²	31.22%	23.84%
Percent of Persons with Disabilities (2003) ³	14.0%	14.8%
Percent of Persons with Difficulty in Self-Care (2003) ³	2.7%	2.7%
Percent of Persons with Difficulty in Self-Care Living Alone (2003) ³	28.6%	23.5%
Number of informal caregivers (2004) (percentage of total population) ⁴	1,900,000 (7.0%)	27,200,000 (9.26%)
Number of informal care giving hours (2004) ⁴	2,000,400,000	29,182,000,000
Value of Informal care giving (annual market value) (2004) ⁴	\$17,623,700,000	\$257,096,000,000

Sources: (1) U.S. Census Bureau Population Division (2004), (2) U.S. Census Bureau, American Community Survey (2004c), and (2004d), (3) National Center for Personal Assistance Services, State Disability Statistics, (4) Friss Feinberg et al (2004).

The growth in NY state's elderly populations is coinciding with an expected decline in the state's non-elderly population. The shift in proportional demographics is magnified by significant out-migration patterns of people aged 20-40 resulting in an expectation in the growth of the number of elderly in New York State by 50.8% between 2000 and 2015 (Prosper, 2002).

NY was predominantly an urban/rural state, with 87 percent of the population living in a metropolitan area (Table 9). NY was one of the wealthier states in the union, ranking 6th in per capita income (\$35,805) and 17th in terms of median household income (\$46,195) (American Community Survey, 2004).

The state has a high poverty rate with 13.5 percent below the poverty line (Table 9). The percentage of aged with incomes below the federal poverty level was 12 percent

as compared to 9.8 percent in the nation (American Community Survey, 2003), and the state had a higher percentage of those not covered by health insurance (15.5 percent) than the national average (15.1 percent). Therefore, the population had higher rates of poverty, especially among the elderly, and less health insurance than many other states.

Table 9. Economic and Political Characteristics, New York and US

	NY	US
State Fiscal Status (State revenue-expenditure (2002)) ¹	-\$14,665,382	
Percent of Population in Urban Area (2000) ²	87.4%	79.01%
Percent of Population in Poverty (2003) ³	13.5%	12.7%
Percent of Aged Population in Poverty (2003) ³	12%	9.8%
Personal Income Per Capita (2003) (constant 2003 dollar) ⁴	\$35,805	\$30,906
Percent of Population Unemployed (2004) ⁵	5.3%	5.4%
Percent of Persons Not Covered by Health Insurance (2003) ⁶	15.5%	15.1%
Percent of Households with Internet Access ⁷	50.2%	50.1%
Percent of Home Ownership Rate (2000) ⁸	53%	66.2%
Percent of Population age 25+ High School Graduates or Higher (2003) ⁸	83%	84%
Percent of Bachelor Level Education or higher (age 25+) (2003) ⁸	30%	31%

Sources: (1) U.S. Census Bureau Source: State Government finances: 2002 (2) U.S. Census Bureau (2004), (3) U.S. Census Bureau American Community Survey, (2004a), (4) U.S. Bureau of Economic Analysis (2003), (5) U.S. Department of Labor (2005), (6) De Navas et al (2004), (7) Friss Feinberg et al (2004), (8) U.S. Census Bureau (2004).

In 2002, the New York state government generated total revenues of over \$104 billion and total government expenditures roughly \$119 billion, resulting in a large deficit (US Census Bureau, 2005) (Table 9). Like many other states, beginning in late 2001 NY's economic picture shifted owing to the emerging national recession. The budget debates in NY involve how the state finances its Medicaid program. Unlike most states, NY counties contribute a significant share of the state financing for Medicaid, equaling about 17 percent of total spending (Coughlin, 2004).

The Governor of NY was Republican, George Pataki. The 53rd Governor of NY, he was elected in 1994 and was reelected in 1998 and 2002. The NY State House of Representatives was comprised of 104 Democrats and 46 Republicans. The state Senate

was comprised of 27 Democrats and 35 Republicans in 2005. In 2006, Eliot Spitzer, a Democrat, became the new Governor.

In 2005, both Republican US Senators from NY, Hilary Rodham Clinton and Charles E. Schumer had a combined Americans for Democratic Action (ADA) liberalism rating of 97.5 percent out of a possible 100, indicating a liberal trend (ADA, 2005). Both Senators Schumer and Clinton are serving their first terms in office, having been elected in 1998 and 2001, respectively. NY had 29 U.S. Representatives, 19 Democrats and 10 Republicans. The Democrats had ADA scores ranging from 75 to 100, with an average of 95.5 out of a possible 100. The Republican ADA scores ranged from 5 to 40, with an average of 25.5, out of a possible 100 (ADA, 2005).

State Medicaid Program

The NY Medicaid program provided services to 3,920,718 million participants in 2002, with expenditures exceeding \$36 billion and a per capita expenditure rate of \$1,052.35 over the national average (Table 10). NY had substantially more Medicaid participants than the average state, with 211.11 Medicaid participants per 1,000 population, compared to the national average of 177.35 participants. The federal government matched NY Medicaid expenditures at the rate of 52.95 percent in FY 2004. However, the federal match (FMAP) for FY 2005 decreased to 50.00 percent, and was to remain at 50.00 percent in 2005-2006 (Kaiser Family Foundation, 2005).

New York spent \$36 billion on its Medicaid program in 2002, and its expenditures per capita were 2.3 times higher than the US average (\$1881.5 per capita compared to \$829 per capita for the US) (Table 10). A public policy report on Medicaid spending in NY documented expenditures as 2.25 times the national average, larger than

California and Texas combined (Public Policy Institute, 1999). In 1997 the program paid out health benefits for some 3.1 million New Yorkers annually, or about one-tenth the state's population, at an average cost per individual recipient of nearly \$7,900. In 2003, a comparison of LTC financing across the states (Gibson et al., 2004), NY ranked number one in total Medicaid spending (in millions) (\$38,480 vs. \$259,565 US), or 15 percent of total Medicaid spending for the US.

Table 10. Medicaid in New York and US, 2002

Medicaid	New York	US
Participants ²	3,920,718	49,754,619
Participant per 1,000 population	211.11	177.35
Expenditures (2003) ²	\$36,046,583,243	\$243,496,863,000
Expenditures per capita ²	\$1,881.54	\$829.19
Federal match (2004) ²	52.95%	
Managed care ²	Yes	
Financial Eligibility (% SSI) ²	300	
Spousal impoverishment rules apply?	Yes	
209b Rules ³	No	
State Supplemental Payment (SSP only) ³	Yes (\$104.)	

Sources: (1) ADA (2005), (2) Kaiser Family Foundation, State Health Facts (2005), (3) National Association of State Medicaid Directors (2003) Also: Centers for Medicare and Medicaid Services (2005), Social Security Administration (2005), and Social Security Online (2004). New York State Medicaid (2005). State Medicaid Eligibility. MI: Department of Human Resources, Division of Health Financing and Policy. http://www.health.state.ny.us/health_care/medicaid/index.htm

Eligibility for Medicaid coverage is determined by state policy, operating under federal guidelines, based on qualifying income and assets. Being eligible for Supplemental Security Income (SSI) automatically qualified individuals who were aged, blind and disabled for Medicaid services as categorically eligible individuals. The maximum federal SSI payment is \$579 for an individual and \$869 for an eligible individual with an eligible spouse. In 2005, New York took the option of supplementing the SSI income provided by the federal government, so that its SSI/SSP standard for an individual was \$666 per month and \$973 for a couple in 2005 (Social Security Income,

2005). NY also offered a medically needy program (Table 10). Thus, NY had generous Medicaid eligibility compared with other states.

NYS does not use the special income standard for institutionalized individuals. The monthly personal needs allowance for nursing facility residents is \$50 for individual, and \$100 for couples. The state uses an amount in the middle as its community spouse protected resource standard, which is \$74,820. The state uses the same income standards for its HCBS waivers. Income eligibility for HCBS waivers is tied to the medically needy income level of \$625 (NY State Medically Needy, 2005). The state does allow spend-down to HCBS waiver eligibility levels, though it does not allow Miller trusts in determining eligibility for HCBS waivers. In regards to cash assistance, NY is a 1634 state (NY State Cash Assistance, 2005).

New York Long-Term Care Programs

This section presents information on four aspects of the publicly funded LTC in NY: (1) Medicaid LTC participants and expenditures by provision type, (2) personal care delivered through Medicaid waivers, (3) other programs delivering personal care, and (4) Community Integration (Olmstead) activity.

NY residents were more likely to use nursing facilities than the national average (5.91 nursing facility participants per 1,000 population compared to 4.80 per 1,000 population nationally). The same held true for ICF/MRs (0.61 per 1,000 for NY compared to 0.42 per 1,000 nationally) (Table 11).

NY residents were more likely to use a combination of home health services, personal care and HCBS or "waiver programs" than were participants nationally. Participants who utilized Medicaid HCBS were 13.62 per 1,000/population as compared

with 8.28 per 1,000 nationally (Table 11). In other words, NY had a 61 percent higher use of Medicaid HCBS than that of the national participant. Of the total number of Medicaid LTC participants in NY, the majority (67.62 percent) were home health, personal care, or HCBS participants. Nursing facility residents made up 29.34 percent, while ICF/MR residents made up 3.03 percent of total Medicaid LTC participants.

Table 11 shows that of NY's \$36 billion in Medicaid expenditures, a little over \$14 billion (39 percent of the total Medicaid budget) was spent on LTC. NY spent approximately \$7 billion on nursing facility care and \$2 billion on ICF/MR facilities. Nursing facility residents received 19 percent of all Medicaid expenditures, even though they constituted only 3 percent of all Medicaid participants. ICF/MR residents accounted for less than 1 percent of all participants, but received 6 percent of total state Medicaid expenditures.

Table 11. New York Medicaid LTC Participants and Expenditures, 2002

	NY	US
Total Population (2002)	18,571,545	280,540,330
Participants (per 1,000 population)		
Nursing facility ¹	109,788 (5.91)	1,346,686 (4.80)
ICF/MR ¹	11,353 (0.61)	117,497 (0.42)
<i>Total Institutional</i>	121,141 (6.52)	1,464,183 (5.22)
Home Health ²	92,715 (5.00)	722,257 (2.57)
PCS ³	88,281 (4.75)	683,099 (2.43)
Waivers ⁴	72,043 (3.88)	920,833 (3.28)
<i>Total HCBS</i>	253,039 (13.63)	2,326,189 (8.29)
<i>Total Medicaid LTC participants</i>	374,180 (20.15)	3,790,372 (13.51)
Expenditures \$ (per capita)		
Nursing facility ⁵	\$6,875,315,483 (\$370.21)	\$46,439,880,813 (\$165.54)
ICF/MR ⁵	\$2,472,622,451 (\$133.14)	\$11,328,435,111 (\$40.38)
<i>Total Institutional</i>	\$9,347,937,934 (\$503.35)	\$57,768,315,924 (\$206.02)
Home Health ²	\$1,076,490,174 (\$57.96)	\$2,837,452,237 (\$10.11)
PCS ³	\$1,940,028,905 (\$104.46)	\$5,593,540,432 (\$19.94)
Waivers ⁴	\$2,075,995,299 (\$111.78)	\$16,880,759,207 (\$60.17)
<i>Total HCBS</i>	\$5,092,514,378 (\$274.21)	\$25,311,751,876 (\$90.23)

Source: (1) CMS (2005a) (2) UCSF Annual Survey Home Health (2004), (3) UCSF Annual Survey PCS (2004), (4) UCSF Annual Survey 372 reports (2004), (5) Burwell et al. (2005).

The percentage of NYS Medicaid LTC dollars spent on HCBS expenditures, including home health, personal care, and waiver services, was 36 percent. NYS Home Health and HCBS expenditures were higher than the national per capita and per participant average in 2002, \$178.93 per capita compared with the national average of \$70.28 per capita (Table 11).

NY spent more than the national average on nursing facility expenditures per participant. Nursing facility residents received 48.5 percent of all Medicaid LTC expenditures, despite constituting only 29 percent of total Medicaid LTC participants. The state spent \$1,753.59 per participant on nursing facilities, and \$1,298.86 on the combination of home health, personal care, and HCBS. ICF/MR expenditures per capita were \$114.93, as compared to \$39.00, the national average. Personal Care and HCBS waiver spending was 23 percent of nursing facility and ICF-MR spending. Nearly 80 percent of all nursing home residents in NY are Medicaid beneficiaries as compared to a national average of 64 percent.

In overall spending, however, NY State spent almost double the amount more on institutional care (\$9,347,937,934) than on combined HCBS (\$5,092,514,378). The percentage of Medicaid LTC dollars spent on HCBS (36 percent) in NY was slightly higher than the national average (30.6 percent). In 2002, NY had more Medicaid LTC participants and expenditures per capita than the national average.

NYS DOH Goals for LTC

In 2002, the NYS DOH examined reports on LTC of reforms in other states, and solicited input from concerned major stakeholders in NYS including study participants interviewed for this study (NYS DOH LTC Initiative, 2002). Participants reported that

the DOH held in-depth interviews with stakeholders, as well as public forums to obtain advice on critical LTC issues facing NYS. Over 200 consumers, providers, advocates and representatives of state and local government from a variety of counties participated in the publicly held forums. Participants shared information on six major themes that emerged (Table 23): public education; personal responsibility; realignment and better coordination of funding; point-of-entry; workforce development; and, regional/ local flexibility.

Table 23. New York State Department of Health Long Term Care Initiative Goals

Public Education:	Elected officials, policy makers and the public must be educated on the impact the aging baby boomer population will have on the future demand and cost for long term care services.
Personal Responsibility:	New Yorkers must assume more personal responsibility for planning and paying for their long term care needs. The growing dependence on government funding must be curtailed.
Realignment and Better Coordination of Funding:	Commercial, public and private funding in the long term care system must be realigned and better coordinated to improve the effectiveness, accessibility and availability of services and to eliminate the fragmentation and duplication of services that currently exists.
Point-of-Entry:	Individuals and their families need a community-based point of entry to the long term care system that offers: a uniform process for assessing personal long term care needs, assistance in the development of care plans, information on services available in the community, and referrals to a choice of appropriate service providers.
Workforce Development:	Current long-term care staffing shortages must be addressed and the work force developed to meet the anticipated need for services over the next several decades.
Regional / Local Flexibility:	Any redesign of the long-term care system must be done in a way to afford regional and/or local flexibility in administering services and programs.

NYS DOH LTC Initiative, 2002

There have been a number of task forces and committees that have studied LTC issues and submitted reports over the past decade in NY (Interim Reform Health Care Working Group Report, 2007). Each group has consistently documented problems common to many LTC throughout the country and some unique to NY, including: lack of coordination, collaboration, and communication among LTC programs and services; service gaps; duplication of services; insufficient or difficult to understand information

concerning PCS service options; lack of choice concerning how services are provided; and, limited or difficult access to consumer-directed options.

Aim 1: Description of NY LTC Programs Including PCS

Aim 1: To describe the NYS PCS program in terms of its governance, organization, and management structure, including the extent of its consolidation, integration, and decentralization.

This section presents the findings relating to the first aim.

Organizational Structure of LTC in New York

The NYS governance and administration of Medicaid LTC programs rests primarily with the DOH, which is designated as “the single state agency” responsible under federal law for supervising the overall Medicaid program and all programs within it. The NYS DOH serves as liaison to the federal government on Medicaid issues and works to: insure compliance with federal requirements; implements eligibility and benefits policies; oversees the Medicaid claims system; and, establishes rates of payment for certain providers (NYSDOH, 2007; Bachrach, 2006).

In NYS, the Office of Medicaid Management (OMM), under the Consumer and Local District Relations Division, is responsible for LTC. The OMM is principally responsible for administering the Medicaid program, overseeing eligibility policy, benefits, systems, federal regulations, practitioner fees, and pharmaceutical reimbursement (Bachrach, 2006). The Office of Health Systems Management (OHSM) is responsible for the oversight of LTC programs under its varied divisions: Division of Health Care Financing encompasses the Bureau of Long Term Care Reimbursement; and the Division of Home & Community Based Care encompasses both the Bureau of

Continuing Care Policy Initiatives & Research and the Bureau of Home Care and Hospice Surveillance & Quality. Most notably, the OHSM is responsible for establishing rates of payment for institutional and LTC providers licensed by DOH (Bachrach, 2006).

Aging programs are also offered by the NY State Unit on Aging (SUA) through the New York Area Agencies on Aging (AAA). It is organized into 59 AAAs that serve each county, the City of New York, the St. Regis Mohawk Indian Reservation and the Seneca Nation of Indians (NYS AAA, 2005). Authorized until FY 2005 under the Older Americans Amendments Act 2000, the National Family Caregiver Support Program aims to stimulate state innovation in assisting families and informal caregivers of older people and seniors who are caregivers and has provided over \$400 million to states and territories since 2001. NY participates in the NFCSP (entitled Elder Care Family Support Program, receiving \$9,510,102.00 in federal funding in 2003).

Funding of Medicaid in NYS

The NYS Division of the Budget (DOB) is responsible for developing the entire \$46 billion Medicaid budget and the state budget (\$114 billion on an all funds basis in 2006-2007) and approves all Medicaid rates, all programmatic initiatives that have a fiscal impact, and the hiring of additional personnel by the agencies (NYSDOB, 2007; Bachrach, 2006).

While the DOH is the single state agency, with legal responsibility for federal compliance and spending, it controls only a portion of the Medicaid program (Bachrach, 2006). More than a dozen NYS entities, 57 counties and NYC, make up the administration of Medicaid. Various state agencies and local governments in NY oversee discrete programs. Specifically, the Office of Mental Retardation and Developmental

Disabilities (OMRDD), Office of Mental Health (OMH), and Office of Alcoholism and Substance Abuse Services (OASAS) each administer sizeable programs funded primarily with Medicaid dollars (NYSDOH, 2007; Bachrach, 2006).

The Medicaid program is a federal-state partnership. Federal rules mandate the benefits that must be offered and the optional benefits. Each state participating submits a “state plan” for Medicaid that meets a rigorous set of standards, some of which may be waived with the approval of the Centers for Medicare & Medicaid Services (CMS, 2007), an agency of the U. S. Department of Health and Human Services that administers Medicaid at the federal level (DHHS, 2007). By agreeing to comply with the rules and requirements of the program, NYS receives federal approval of their plan and is entitled to a federal contribution to their Medicaid program. Generally speaking, the richer the state the less money it gets from the federal government to pay for Medicaid. Overall federal matching rate for NY is 50 percent, the lowest offered, as opposed to Mississippi at 76 percent matching, the highest (FMAP, 2007).

Cost Containment Measures for Personal Care Services in New York

The Bureau of LTC Reimbursement sets the Personal Care Rates for the PCS program and CDPAP. The initial rates are all-inclusive and are based on the lower allowable cost (held to ceiling) projected over the following two year period or the established charges as reported by each agency. Included in the rate setting are trend factors, administrative and general caps, aide and training ceiling, capital costs, and profit/surplus percent, as explained by a fiscal analyst from the department (Fiscal Analyst, OHSM, 2006).

Trend factors are based on Section 21 of the Health Care Reform Act (HCRA) 2000, which requires that effective April 1, 2000 the trend factor be calculated using proxies based on the Consumer Price Index (CPI) (HCRA, 2000). Trend Factors shift yearly. For example, the Trend Factor for 2005 was 2.00 percent and with an increase to 2.5 percent for 2006.

Administrative and General caps, pursuant to Title 18 NYCRR Section 505.14 (h)(7)(ii), the amount which may be paid for administrative and general costs in the personal care rates is limited to no more than 28% of the total costs reported by an agency (DOH LTC Rates, 2005). This is true for the PCS program, except for NYC and the CDPAP, which are explained below.

The combined direct care and training cost are compared to the regional ceiling for each service level and vary based on the rate component used in the calculation which is the lower of a provider's combined trended costs (DOH LTC Rates, 2005). The expenditure items included in the capital costs as identified in the cost report include, for example, rent of buildings, equipment, and vehicles, interest on property and depreciation (DOH LTC Rates, 2005).

Profit/Surplus Percent is determined by calculating the ratio of the provider's allowable costs for aide wages and benefits to the provider's total allowable personal care services costs, multiplied by the published rate for six-month treasury bills. Each base rate is multiplied by this percentage to determine the amount added to the provider's rate for profit/surplus. For example, the published rate for six-month treasury bills as of September 30, 2005 is 3.745 percent. Section 505.14 (h)(7)(ii) states that when the treasury bill rate has increased or decreased from the previous applicable treasury bill rate

by more than two percent, the Department will consider only a two percent increase or decrease in the treasury bill rate when determining providers' adjustments for profit or surplus for a particular year (DOH LTC Rates, 2005). The profit/surplus margin for 2005 was 1.95 percent. Therefore, the percentage used in the profit/surplus adjustment for 2006 will be the published Treasury bill rate of 3.745 percent. Cost containment policies vary county to county and are not consistent throughout the state. Evaluation tools vary by county and account for the variation in hours of service needed as noted by intake evaluations.

Rate Setting for the Consumer Directed Personal Assistance Program

In 2005, the DOH implemented an updated methodology for the calculation of 2006 rates for payment of the CDPAP service. Based on concerns raised by LDSS staff, Department staff and home care providers, the Division of Health Care Financing reevaluated the rate methodology and made changes that include, primarily, an administrative cap of 18% based on 2004 actual allowable cost data for consumer directed providers (DOH LTC Rates, 2005). In addition, the payment system began accepting quarter hour rates for the CDPAP services effective 1/1/06 (DOH LTC Rates, 2005).

Rate Setting for Small Population Areas

Worker Recruitment and Retention is an adjustment rate authorized to provide payment to personal care providers located in local social service districts which do not include a city with a population of over one million persons, for purposes of improving recruitment and retention of personal care services workers (DOH LTC Rate, 2005). Interviews with a number of state officials confirmed the increasing lack of an available

PCS workforce in upstate NY. Section 367-q of the Social Services Law authorizes an adjustment amount to a provider's rate determined through a proportional allocation based on each PCS provider's total annual hours of PCS provided, as reported in each providers' cost report (DOH LTC, 2005). New York City, being a city larger than one million, is not included in this rate adjustment. Cost neutrality is a federal requirement of waiver applications. Some of the ways that cost neutrality can be achieved are: 1) an individual cap (e.g. the LTHHCP), or an aggregate cap (e.g. the TBI waiver).

Rate Setting in New York City

NYC started the personal care aide program and, because of that, they developed the wages. Originally, the personal care aides were city employees. When CMS came in (HCFA at the time), it told NYC that it could not employ the workers, that they had to be, as one city officials stated, "an arm's length distance in their relationship". At that point, NYC went out and negotiated with not-for-profit entities to assume the responsibility for the program. And NYC negotiated the rate.

To this day, according to one city official who reports that 80% of PCS for NYS continues to be provided in NYC, the CMS supports and maintains that there is a different relationship between the PCS program and the state and NYC, mostly having to do with the spend-down. Meaning, that a consumer may be in need of LTC or, specifically, PCS, there's a special arrangement that approved by HCFA (now CMS) whereby the individual, the provider, bills the individual for the difference. For example, suppose its \$300. / Month. The individual pays the provider \$300. /month and then becomes fully Medicaid eligible for everything. This is an arrangement between CMS and NYC. It is not available in the Certified Home Health Aide (CHHA) program. It's

only with the PCS program and only available in NYC, not upstate NY. It's a special arrangement between HCFA (now CMS) and NYC. According to one city official, there have been suits and appeals to challenge this agreement to no avail and, after going through the whole process, it still stands.

The State has to approve the final rate NYC negotiates with providers but the city's rates are less than what they pay upstate. The providers bill Medicaid for the rate that has been contracted per hour. The city bills per hour of service as determined by the CASA, whatever hours each client is eligible for. The provider assigned to that client then bills Medicaid for those hours and gets paid for only the hours served. It's an automated system through HRA whereby the city sends the hours to the state for Medicaid billing for the authorized number of hours for each client. This is done on a weekly basis, an automatic process. And then the provider submits the bill to Medicaid for the actual hours served. And there is an alternative system whereby the personal care attendant plugs into the system by confirming their actual presence in the clients home by picking up the client's telephone at the time of their arrival to confirm they have arrived and calling into the system again at the time of departure to code into the phone the actual services performed for the day. There is then a reconciliation of the hours actually served and those billed. Each provider has a contract with the city with negotiated rates established. And then the city notifies the state that this is the negotiated rate and the state approves it.

Every six years, HRA puts out to bid a Request for Proposal (RFP) process and provider agencies go through the whole process of submitting their RFP responses. When a provider agency is awarded the contract provision (the city refers to this as the PBB

rules), city rules state that the contract is for two years, at the end of which the provider can receive two renewals, for two years each, for a maximum of six years. It is a big process for each agency and there is no assumption that any one agency will continue to have a provider contract unless it meets all the requirements and criteria. Many of the current provider agencies are very well established, and those that aren't fall to the wayside. HRA has a staff team that screens proposals and visits the facilities to document that the providers actually fulfill the criteria. Typically, according to one official, those that have been in business and well established are better able to meet the criteria.

Cost Growth in the PCS Program in NYC

During the last twenty-five years, both NYS and NYC have experienced periods of considerable expansion in Medicaid expenditures (Schick & Balinsky, 2005), challenging the HRA to consider different ways to deliver PCS that are required by individuals, but at a reduced cost. The demographic shift of growth in the aging population of NYC has resulted in a higher volume of consumers receiving care, and increase in the number of units (hours) of care and an increase in the cost per unit of care (Stone, 2000). The expansion of the PCS program in NYC alone has jumped from approximately 2000 cases in 1994 to 46,000 in 2004 to 63,000 in 2006. Costs for the PCS program has also grown from approximately \$26 million in 1975 to \$1.4 billion by 2002 and \$2 billion, currently (Interview with NYC officials, 2007).

Several ways of addressing the growth of the PCS program have been considered over the years of the program. Limiting or reducing the number of consumers eligible for the PCS program was not an option since Medicaid is an entitlement program, and neither NYS nor NYC has the ability to limit the number of recipients who are eligible.

Reducing the average number of hours of service received by each recipient, however, was attempted as a cost savings option (Schick & Balinsky, 2005).

Task Based Assessment was an attempt by NYC to reduce average weekly hours and costs, though it did not work effectively for a number of reasons. The Task Based Assessment may not have been implemented as HRA or contract agency staff, sympathetic to clients, exercised discretion in providing more hours than required by the new Task Based Assessment methodology (Schick & Balinsky, 2005). Alternatively, it's possible that clients entering the PCS program have become higher acuity and need more hours of service to remain in the home and community setting. And, finally, HRA was faced with a number of lawsuits, including *Mayer v. Wing* (1996) that challenged HRAs ability to adjust hours of service if there was no change in the client's condition or circumstance. In particular, the Mayer case had a significant impact on the implementation of the Task Based Assessment methodology as HRA could not reduce service hours with the new evaluation instrument if a client's condition or circumstances remained the same (Schick & Balinsky, 2005). Most recently, cases that normally are referred to the HRA for assessment into the PCS program are being sent to the NYS Medicaid Managed LTC Program. State and City officials, and provider agency directors, all spoke of the Managed LTC Program being advantaged in cost savings by drawing the healthiest, least acute clients, leaving clients that, on average, required more hours of services and thus costs of the program. While an exact analysis of the cause for why is not precisely clear, Task Based Assessment did not reduce the average weekly PCS hours and their associated costs (Schick & Balinsky, 2005).

Shift from PCS Program to Medicaid Managed Care Programs

The current system of providing LTC services to clients in NYS has been described as “fragmented” and causing problems for both clients and the providers of these services (Schick & Bolinsky, 2005). Problems stem from clients being required to be seen and assessed by different health care professionals from different provider organizations to deliver services. Likewise, there is a problem for both clients and provider organizations in terms of coordinating care, the continuity and reassessment of care needs, and the important issue of consumers having more direction over the provision of services provided to them, all reasons for the single-point of entry initiative. Managed Long Term Care Programs, for example VNS CHOICE, have demonstrated an approach to effectively control PCS while providing clients with the services they need (Schick & Bolinsky, 2005). The PCS program in NYC has not been as successful in demonstrating this ability and has had its average PCS hours per case increase over the years. One approach to both improve the management of PCS and eliminate the fragmented LTC services received by recipients in need of these services is to expand and move clients from the PCS program to Managed LTC Plans. There is an assertion that clients would be better served. Enrollment in Managed LTC is voluntary and, at any time, if the client is dissatisfied, they can return to the PCS program.

One review of the Task Based Assessment mode (Shick & Balinsky, 2005) reported that it did not demonstrate cost effectiveness for NYC as a whole when measured by hours per case over time. The “cherry picking” of the best clients by the Managed LTC programs is one reason HRA and provider agency staff report an increase in the acuity of participants in the PCS program. There is some thought that, because the

PCS program only offers one type of LTC (PCS), this is a limitation and government should work to expand the Lombardi Waiver Program or MLTCP, such as VNS CHOICE, rather than attempt to achieve further savings for the PCS program (Shick & Balinsky, 2005; Interviews with HRA, 2007).

Personal Care Services in New York

Since 1982, the NYS Medicaid Personal Care Services (PCS) program has offered a state plan optional benefit for PCS. Defined in the NYS DOH laws and regulations, Title 18 Section 505.14 (2006), the program defines PCS as some or total assistance with personal hygiene, dressing and feeding, nutritional and environmental support functions, and health-related tasks. Such services must be essential to the maintenance of the patient's health and safety in his or her own home, as determined by the social service district in accordance with the regulations of the DOH; ordered by an attending physician and based on an assessment of the patient's needs and of the appropriateness and cost-effectiveness of services. A plan of care, supervised by a registered nurse, is required. Continuous 24-hour PCS are offered and mean the provision of uninterrupted care, by more than one person, for a patient who, because of their medical condition and disabilities, requires total assistance with toileting and/or walking and/or transferring and/or feeding at unscheduled times during the day and night (Title 18 Section 505.14, 2006).

Eligibility Criteria

The NYS PCS program eligibility criteria states that the social services district determines that PCS are, or continue to be, medically necessary and expects that PCS can maintain, or can continue to maintain, the client's health and safety in his or her home.

In spite of budget deficits, there were no limits to the maximum cost of care or hours of care per recipient for the NYS PCS program. A social services district determines whether a client is eligible to receive personal care services, provided that the services are medically necessary and are reasonably expected to maintain the client's health and safety in his or her home, as determined by the social services district in accordance with the regulations of the DOH; or whether such client must be referred to other long-term care services.

Traditional PCS Program

The PCS program requires that the patient's medical condition be stable and not be expected to exhibit sudden deterioration or improvement nor require frequent medical or nursing judgment to determine changes in their plan of care. Basically, it's a program that requires that a physically disabled individual or frail elderly be in need of routine supportive assistance and not need skilled professional care in the home, and yet require assistance to prevent a health or safety crisis from developing.

The PCS program states that the program shall be self-directing, meaning that the patient is capable of making choices about his/her ADLs, understanding the impact of the choice and assuming responsibility for the results of the choice (Title 18 Section 505.14, 2006). Patients who are not self-directing, and who require continuous supervision and direction for making choices about ADLs may receive PCS only if the responsibility for making these choices is assumed by a self-directing individual living within the same household or by an outside agency or other formal organization. The local social services department may be the outside agency.

The PCS program provides services such as housekeeping, meal preparation, toileting and grooming and is available through Medicaid, private payment, and some health insurers. For Medicaid-eligible persons, local social services districts usually contract with homecare agencies that employ aide to provide Medicaid personal care services. For a person to receive services, his or her doctor must send a completed Physician's Order to the local social services district, which then arranges a social and nursing assessment of the individual. A nurse assessor uses the results of the assessments, together with the physician's order, to recommend an appropriate amount, frequency and duration of services. The local social services office then notifies the individual of the services that will be provided. *The traditional* PCS program described above was the only option for individuals until the consumer-directed program, explained below, was included as an alternative choice for eligible participants in the program after 1995. The need for services is reassessed approximately every six months. The DSS 3139, the home assessment abstract, is the uniform assessment form used throughout the state except for NYC, which has its own, approved, assessment form.

Consumer Directed Personal Assistance Program

In the late 1980s the New York Department of Social Services implemented a pilot program entitled *The Patient Managed Home Care Program* that became the present consumer-directed division within the NYS Medicaid PCS program, the Consumer Directed Personal Assistance Program (CDPAP).

First established in NYC by a small group of disabled individuals who incorporated as an entity in 1977, Concepts of Independence for the Disabled, Inc., was established in order to promulgate the concept of self-direction. The NY Legislature

enacted the Consumer Directed Personal Assistance Program (CDPAP) in 1995 (Article 5, Title 11, § 365-f) and changed the name from The Patient Managed Home Care Program to the CDPAP, placing the program within the NYS DOH, Bureau of Medicaid Operations. The CDPAP operates as a Medicaid home care services program funded under the State Medicaid Plan's PCS program benefit. All guidance of the program is within the PCS program regulations (18 NYCRR 505.14). The CDPAP is an alternative PCS program offered within the established, *traditional* PCS program.

The CDPAP allows the consumer to select, supervise, and train a personal assistant of their choice to provide the authorized hours of care. The NYS Nurse Practice Act is waived for the CDPAP (provided under S3622, public health, or S365f, social service, laws) so that the consumer may train the personal assistant to carry out skilled nursing services and/or invasive interventions that are not permitted within the traditional NYS PCS program. This exemption, modeled from consumer-directed models adhere to the principle that, "individuals have the primary authority to make choices that work best for them... regardless of the nature or extent of the disability or the source of payment for services" (National Institute on Consumer-Directed LTC Services, 1996), allows the nurse to educate the consumer and the assistant, and monitor the services over time, but not hold the nurse responsible for the actual provision of the care (Reinhard, 2001).

Other principles and guidelines unique to the CDPAP and articulated by the Consumer-Directed Personal Assistance Association of New York State (CDPAANYS) include allowing consumers to independently recruit, hire, train, supervise and, if need be, terminate the personal assistants they choose to work with. While the consumer may hire anyone, members of the CDPAANYS do not condone a surrogate (self-directing other)

working as a personal assistant while managing the program for a consumer. The CDPAP provides discrete program monitoring within the context of the consumer's responsibilities so that if any issues arise the program can work with the consumer, and the county caseworker, to rectify the issues. To permit the program to empower consumers, programs avoid using any system that bypasses the consumer, even if the system is technologically superior or administratively easier. The CDPAP providers keep the consumer actively involved in the enrollment, time sheet data collection, and payroll distribution processes. This involvement significantly enhances the consumer's sense of authority over the personal assistant management process, even if the program's design makes this involvement technically symbolic.

In 1996, the legislature passed Social Services Law 365-f establishing the CDPAP to support chronically ill and/or physically disabled individuals receiving home care under the Medical Assistance program greater flexibility and freedom of choice in obtaining such services. The CDPAP is operated in NYS as a Medicaid State Plan service, under the PCS program benefit. As such, until discrete regulations governing the CDPAP are issued by the DOH, districts must follow all applicable PCS program assessment and authorization process and policies. The scope of services that may be authorized under the CDPAP include the scope of tasks that may be provided by a Personal Care Aide (PCA), Home Health Aide (HHA), Licensed Practical Nurse (LPN) or Registered Professional Nurse (RN).

Medicaid Waivers - 1915(c) Waivers

New York offers a number of long term care programs including PCS, waivers, and home health care. In 2006, NY had eight Medicaid 1915 c waivers in operation,

providing a range of population groups with home and community-based services (described in Table 12 below).

Table 12. New York Medicaid 1915(c) Waivers

Waiver	Description
Long Term Home Health Care Program	Administered by DOH for persons who are elderly or disabled and who require nursing home level of care.
OMRDD Waiver for Adults and Children with Developmental Disabilities	Administered by DOH and OMRDD for adults and children who are developmentally disabled and who require intermediate care facility level of care.
OMH Waiver for Children with Serious Emotional Disturbances	Administered by DOH and OMH for children who are seriously emotionally disturbed and who require psychiatric hospital level of care. (Available in selected counties in NYS; provides for PCS).
Care at Home I and II	Administered by DOH for children under the age of 18 who are physically disabled and who have had a 30-day inpatient stay but who are not eligible for Medicaid due to parental income and resources.
Care at Home III, IV, VI	Administered by DOH and OMRDD for children under the age of 18 who are developmentally disabled, have complex health care needs, and require intermediate care facility level of care but who are not eligible for Medicaid due to parental income and resources.
Traumatic Brain Injury	Administered by DOH for persons age 18 and over who have experienced a traumatic brain injury and who require nursing facility level of care.
Partnership Plan	Administered by DOH, this waiver mandates enrollment of Medicaid beneficiaries into managed care plans, with some exemptions and exclusions. An amendment to this plan created the Family Health Plus program for low-income, uninsured adults.
Nursing Home Transition and Diversion Waiver (Approval pending with CMS)	This waiver program will be administered by DOH for individuals 18 and over with disabilities who require the level of care provided at a nursing facility but can be treated in a community-based setting.

Bachrach (2006). Administration of Medicaid in New York State prepared for the Medicaid Institute, United Hospital Fund.

New Demonstration Waiver for New York

On September 29, 2006, CMS approved a NYS for waiver authority for a new 1115 demonstration waiver, NY Federal-State Health Reform Partnership (FSHRP, 2007), to be implemented on 10/01 and set to expire 9/30/11. Through this demonstration, the federal government and the State of New York will partner to restructure New York's health care system. Under F-SHRP, the State will invest up to \$1.5 billion (up to \$300 million per year) in agreed upon reform initiatives. The primary focus of these initiatives

will be to right size and restructure the acute and long-term care delivery systems, expand the use of e-prescribing, foster the implementation of electronic medical records and regional health information organizations and expand ambulatory and primary care services. NY will be required to meet a number of programmatic milestones during the demonstration, as well as demonstrate Medicaid program savings from both the health care system reforms that it will be implementing, as well as expansion of managed care enrollment to additional counties in the state. NY will also be required to conduct an evaluation of the impact of the demonstration program during the 5-year period.

NY will implement a significant restructuring of its health care delivery system as part of fundamental program initiatives by: reducing excess capacity in its acute care hospital industry; shifting emphasis in long-term health care services from an institutional to a community-based setting consistent with the President's New Freedom Initiative by reducing nursing home excess capacity and worker retraining; investing in health information technology initiatives, including e-prescribing, electronic medical records and regional health information organizations; and, reorienting NY's health care system away from inpatient facilities to outpatient and primary-care focused delivery systems, including pay-for-performance initiatives.

The Long Term Home Health Care Program

The NY OMM and OHSM include The Long Term Home Health Care Program (LTHHCP) waiver when discussing programs offering LTC, however, the LTHHCP does not offer PCS. Both programs are combined by the OHSM when calculating overall costs of LTC in NYS. The LTHHCP waiver is a smaller, coordinated plan of care and services for individuals who would otherwise be medically eligible for placement in a

hospital or residential health care facility for an extended period of time if such a program were unavailable (LTHHCP, 2006). Also known as the *Lombardi Program* (named for the legislator putting the plan forth) or the *Nursing Home Without Walls program*, the LTHHCP can be provided in the person's home, an adult care facility (other than a shelter for adults), or in the home of a responsible adult. While PCS are not provided to participants in the LTHHCP, NYS has a 1915 (c) waiver from the federal government that enables the state to provide participants with a number of services through the LTHHCP that are not available under the State Medicaid PCS program. The enabling legislation, Social Services Law § 367-c, authorizes LTHHCP services to be provided when the total monthly Medicaid expenditures for health and medical services for an individual do not exceed 75% of the cost of care in either a skilled nursing facility (SNF) or a health-related facility located within the local district. The costs of services for an individual can be averaged over 12 months to ensure that the annual cost of care remains under the 75% cap. Recently, NYS has approved significant expansion of the program with plans to add 8 new Lombardi providers and approximately 1,125 new slots (Hacker, 2006).

Like other states, NYS utilizes various waivers (certain requirements are waived) to provide care to specific groups of consumers. In regards to LTC, the LTHHCP is the HCBS waiver under section 1915 (c) of the Social Security Act that gives NY flexibility to offer services other than PCS under the purview of the OHSM and OMM. All waivers must be budget-neutral, in that they may not cost the federal government more than the cost of operating the program in the absence of a waiver. Thus, eligible participants may receive PCS through the PCS program and, at the same time, receive other services from

a waiver program. The only waiver program offering PCS in NYS is the OMH Waiver for Children with Serious Emotional Disturbances.

NYS Managed Long Term Care Plans

The NYS Managed Long Term Care Plans (MLTCP) is another, newer program for LTC and has two basic models, the Program of All Inclusive Care (PACE) and the partially-capitated MLTCP (Shick & Balinsky, 2005). As of May 2003, there were four PACE programs and 11 partially-capitated MLTCP plans in NYS (NYSDOH, 2004). In 2002, Medicaid capitated payments to NYS MLTCPs were \$340 million (Shick & Balinsky, 2005). In 2003, there were 9,078 enrollees in all MLTCPs, anticipated to grow and, although these numbers are not large when compared to the total elderly Medicaid recipients in NYS, they represent the nation's largest number of community-dwelling Medicaid eligible participants serviced by capitated LTC plans (Shick & Balinsky, 2005). In NY, the MLTCPs started in 1997 and grew to almost 10,000 clients by 2004 (Shick & Balinsky, 2005). This alternative Medicaid Managed program now represents a significant alternative to the PCS program for eligible participants in NY and was repeatedly cited by directors of provider agencies in NYC for "skimming" the less acute Medicaid recipients, leaving more acute clients for the PCS program. The Visiting Nurse Service of NY (VNSNY) is one of the organizations operating a MLTCP in NY, VNS Choice. Starting as a demonstration program in 1998, VNS Choice has grown and had 3,793 clients as of June 2004 (Shick & Balinsky, 2005; VNSNY, 2007).

Simultaneous Program Participation

Typically, a person in need of LTC would participate in only one of the two programs, the PCS program or LTHHCP, and not receive services from both at the same

time. The DOH, however, clarifies that, in some instances, the local social services district may determine and document in the case record that a person in need of LTC services is appropriate for participation in both programs. This may happen, for example, when the LTHHCP does not have sufficient paraprofessional staff to meet all of the health care needs identified in the consumer's care plan; or when the geographic location of the consumer makes provision of all of the consumer's service needs difficult to consistently provide. When considering the appropriateness of an individual's simultaneous participation in both programs, the social services district must first determine that the person meets the eligibility criteria of both programs. The local district social services provides administrative management of the person's overall service plan by assuring that each program's care plan is compatible with the other programs and that the provision of services is provided in accordance with each programs respective governing regulations and policies, assuring that the services authorized under each program are not duplicative, and that the consumer's participation in both programs is necessary and appropriate.

Coordination of LTC and the PCS program

Prior to 1995, the Department of Social Services (DSS) managed the NYS Medicaid PCS program. During 1995-1996, the Department of Social Services (DSS) was absorbed into the DOH. Presently, both agencies have program responsibilities in implementing the program. Experienced staff from the DSS was also absorbed from the DSS to the DOH. The transition from one department to the other of state officials familiar with the program appears to be a strength and source of institutional history within the program. This retention of staff from DSS to DOH also appears to provide a

reason there is strong imprinting for a status quo situation within the administration of the program and reason for inertia in progressing to a stronger consumer-directed PCS program in NYS.

Although primary administration of NYS Medicaid PCS program is at the county level, all providers are assigned to one of the following five regional groups: 1) the Metropolitan Downstate Group, which includes providers located in Nassau, Rockland, Suffolk, or Westchester county; 2) the Metropolitan Upstate Group, which includes providers located in Albany, Broome, Dutchess, Erie, Monroe, Niagara, Oneida, Onondaga or Orange County; 3) The Suburban Group, which includes providers located in Cayuga, Fulton, Genesee, Madison, Montgomery, Ontario, Oswego, Rensselaer, Saratoga, Schenectady or Wayne County; 4) The NYC Group, which includes providers located in the five boroughs of NYC; and 5) the Rural Group, which includes providers located in any of the remaining 33 social services districts not included in the Metropolitan Downstate, Metropolitan Upstate, Suburban or NYC group (New York State Plan Personal Care Program, 2005).

The Human Resources Administration, New York City

The Human Resources Administration (HRA), created by Mayor John Lindsay's executive order in September 1966 (HRA Executive Order No. 28, 2007), is the umbrella organization for the DSS in NYC. Created to better coordinate and integrate NYC's human services programs, HRA is responsible for the NYS Medicaid PCS program for NYC. HRA is also the umbrella organization for Adult Protective Services; the Department of Welfare; the Manpower and Career Development Agency; the Community Development Agency; the Youth Services Agency and Addiction Services Agency.

In noting the distinction between PCS and home health care, in NYC PCS are currently provided for Medicaid-eligible consumers by 95 vendors who are licensed by the NYS DOH and have a contractual relationship with HRA (Hacker, 2006). The largest number of clients receives PCS provided by trained home attendants in the PCS program, but the HRA's Home Care Services Program also facilitates access to other LTC programs, including the Lombardi (waiver) Program.

Home health care, on the other hand, is provided by Certified Home Health Agencies (CHHAs) who are certified by the NYS DOH. While home health care is overseen by the DOH, CHHAs do not contract with HRA, and HRA does not have oversight over them. Consumers may be referred to CHHA services through several entities, mostly hospitals. Home health care is a relatively short-term method of providing sub-acute ambulatory care interventions. Many cases that had previously been receiving CHHA care are eventually transferred to the HRAs Home Care Services Program for PCS (Hacker, 2006), either the traditional PCS program or alternative CDPAP or the Lombardi waiver program.

In recent years, NYC has experienced a pattern of an increase of participants in the Lombardi program and a decrease in the PCS program. This is a clear investment by the state to offer the Lombardi program due to it offering a greater array of services, including home modifications. In addition, as the state approaches restructuring LTC, they are giving serious credence to models that allow a consumer to move from one kind of service to another seamlessly.

Assessment Tools

Various assessment tools are used in NYS to assess the needs of participants in the various programs offering HCBS in NYS. An alternative service delivery to the PCS program, VNS CHOICE, provides training to assist its staff to more effectively assess the need for services by providing a consistent process for clinical decision-making that helps maintain financial viability of their Managed Long Term Care Plan (MLTCP)(VNSNY CHOICE, 2007).

Visiting Nurse Service of New York (VNSNY) CHOICE uses a comprehensive assessment to evaluate each client's clinical, functional, and cognitive status (VNSNY, 2007). Data from the Outcome and Assessment Information Set (OASIS) is incorporated into the nursing assessment instrument (Center for Health Services and Policy Research, 2000). This data set was developed by the Center for Health Services Research for the US Department of Health and Human Services. The assessment tool used by VNS CHOICE is more extensive than the M27R used by HRA for assessment of PCS program participants.

There are additional areas in which comparisons can be made between VNS Choice's management of their PCS hours and the NYS PCS program. VNS CHOICE pays special attention at the time of assessment for new cases since that it the best opportunity to ensure that consumer's receive PCS that are supported by assessed needs. Consistent with what City officials at HRA explained, VNS CHOICE reports that it is much more difficult to reduce the level of care once service has begun than to begin service with a given level of care and increase it in the future as needs increase.

VNS CHOICE spends two to three visits in the client's home to enroll them in the program, what they refer to as "informed enrollment", to assist the consumer and their family to understand the program, how it works, and each party's responsibility in the care of the client. VNS CHOICE is able to do this extensive enrollment and assessment process as they have a ratio of clients to nurses of approximately 20 to 25:1.

The NYS PCS program assessment process is not as comprehensive, primarily due to far higher staffing ratios. HRA, via CASA nurses, serve as the entry point for all PCS program and assess new clients using the M27R Form. According to NYC officials, the CASA nurse assesses approximately 4 new clients a day before passing them on to provider agencies under contract with the city. The provider agencies have a client/nurse ratio of about 125:1 (Shick & Balinsky, 2005), confirmed by interviews with HRA staff, or approximately one-fifth of the coverage of VNS CHOICE and other alternative Managed LTC Programs. Additionally, because VNS CHOICE is a full scope LTC program, they have other services in addition to PCS while the PCS program only offers PCS.

Litigation and Appeals Process

A number of lawsuits are shaping the policies and procedures for HCBS in NYS. Since the landmark interpretation of the ADA, states have acted to comply with the Supreme Court's Olmstead decision. The Center for PCS has tracked 6 Olmstead related cases in NYS (NYS Olmstead and Olmstead-related Lawsuits, 2007) with information and summations of the cases to-date. Four of the cases have closed or were settled and two cases brought forth in 2003 remain open. The NYS DOH website reports on the suits that apply to personal care services regulations. For example, in the case of Mayer v.

Wing, Medicaid beneficiaries challenged termination of home health services & referral for nursing facility placement after the state determined home health was no longer cost-effective because it exceeded 90 percent of the average cost of a nursing facility. The court prevented the state from terminating the services, as the state failed to show that continuing to provide services would fundamentally alter its program. The court also found that Olmstead covers people with physical &/or sensory disabilities as much as mental or emotional disabilities.

New PCS regulations were adopted to comply with court rulings in the lawsuit to remind districts of State requirements affecting client notices and districts' assessments of recipients whom districts determine require 24-hour care. The new regulations, effective November 1, 2001, provided that the district's "determination to reduce, discontinue or deny a client's prior authorization must be stated in the client's notice". Although not a new regulation, there is now a clear directive for consistency in having the client notice explain why change in the client's circumstances results in the need for fewer hours of service. When districts determine to reduce, discontinue or deny PCS, the client notice must identify the specific reason (for example, whether a prior mistake in the authorization, the client's refusal to cooperate with the required assessment or other specific reason set forth in the regulations) that justifies the action. The client notice must also explain why the cited circumstances or event necessitates the reduction, discontinuance or denial of services.

Eligibility Criteria

New York State Plan personal care service eligibility criteria states that the social services district determines that personal care services are, or continue to be, medically

necessary and expects that personal care services can maintain, or can continue to maintain, the client's health and safety in his or her home, as determined in accordance

In spite of budget deficits, there were no limits to the maximum cost of care or hours of care per recipient for the NYS PCS program. A social services district determines whether a client is eligible to receive personal care services, provided that the services are medically necessary and are reasonably expected to maintain the client's health and safety in his or her home, as determined by the social services district in accordance with the regulations of the DOH; or whether such client must be referred to other long-term care services.

Service Authorization

Personal care services, as defined by the NYS PCS program, can be provided only if the services are medically necessary and the social services district reasonably expects that the patient's health and safety in the home can be maintained by the provision of such services, as determined in accordance with the regulations of the DOH (New York State Plan Personal Care Program, 2005). Both registered nurses and social workers may assess client's need for the PCS program; however, the registered nurse is responsible for authorizing the services based on the assessment.

Difficult to Serve Participants

PCS program participants that require considerable attention, for a variety of circumstances, are assigned to one of three PCS provider agencies (Personal Touch, Metro, and HANAC) contracted with HRA specifically to serve *difficult to serve* participants. Individuals within this category may be, for example, difficult to serve due to mental health issues, requests for specific caregiver requirements (e.g. language), have

particular family dynamics that require special attention to meet the needs of the participant, or live without a telephone or in an unsafe living situation or other geographic considerations. Difficult to serve clients make up a small percentage of overall participants. For example, as of October 2006, there were approximately 64,407 participants in the PCS program in NYC, according to HRA officials interviewed. Of those, approximately 200 were categorized as *difficult to serve* and having their PCS needs addressed by one of the three designated provider agencies contracted to handle this group of participants. Directors from the three provider agencies providing care to this group of participants stated that they provide additional training to the staff assigned to difficult to serve cases and spread the workload around, not limiting any one staff member to carry a caseload of clients in this category.

Process for Participating in PCS in New York City

A client's physician must fill out a Medical Request for home Care Services Form M-11Q. The M-11Q form is where the physician explains why a client consumer is unable to carry out certain ADLs on his own. It also lists all prescribed medications the consumer is currently on. After the M-11Q is complete, it is sent to a local HRA/Community Alternative Systems Agency (CASA). Once the CASA office receives the Form M-11Q its Central Intake Unit gets in touch with the consumer within 3-5 business days. The Form M-11Q is assigned to a home care staff member for pre-screening. The staff member will review it to make sure it is complete and has been submitted in a timely manner. Central Intake Unit staff may call the consumer to ask questions about eligibility. If the consumer is Medicaid-eligible, a CASA nurse will make a home visit to do a medical assessment, Form M27R, and a CASA case manager will visit the consumer

at home to assess their social situation. The case manager will assess the home environment and ascertain if there are family members and/or friends to assist with some of the tasks the consumer cannot do for themselves. If the consumer does not have Medicaid, the case manager will bring the correct Medicaid application and assist with the application process.

It may take up to 30 days to be accepted for home care services and to find out the number of hours allotted for assistance. The CASA Medical Review Team provides the initial assessment and decides the level of care that is right for each potential client. The consumer then receives a notice alerting them if their case has been accepted for services. To receive NYC home care services, a consumer must also have Medicaid. According to city officials, it takes up to 30 days for a consumer to know if they are eligible for homecare, but the application for Medicaid may take 45 days to resolve, and may require additional information from the consumer.

To know if homecare is right for them or not, a consumer or a family member must be able to direct the homecare worker. If a client requires more than PCS and chore services, such as changing dressings or the checking of blood pressure, then they may be eligible for other programs, such as the Lombardi (waiver) program or services from a CHHA, which can provide a full array of LTC services for those who need a higher level of skilled care.

After being approved for the Medicaid-funded PCS program the case will be assigned to a Medicaid-contracted Home Care Provider Agency in the consumer's neighborhood. The Provider Agency will contact the client to arrange for their nurse and assigned home care attendant to go to the consumer's home to meet with them. At that

time, the nurse will review the plan of care with you and your attendant and the initial date of service will be established. The Home Care Services Program preauthorizes the weekly number of hours to be provided based on the determined level of need. When both the plan of care and Medicaid coverage are in place, the client is assigned to a contracted provider within the five boroughs. Each client has a caseworker assigned to be responsible for ongoing oversight of the case, including service reauthorization at least annually. Clients receive a Form M-11Q in the mail about 60 days prior to the reauthorization date. The client then arranges to get the form completed by a physician as soon as possible.

CASA case managers are available by phone to assist if the consumer has questions. If a client has a problem with a Provider Agency that is providing home care, they can call the Home Care Complaint Tracking Unit (CTU) and discuss the issues. The CTU is available on a 24-hour basis, with staff members available Monday-Friday, 9-5.

Table 13. NY PCS Program Needs Assessment & Authorization, 2002-2005

	2002	2003	2004	2005
<u>Non-physicians</u> assess client's needs for State Plan PCS	Y (RNs & SWs)	Y (RNs & SWs)	Y (RNs & SWs)	Y (RNs & SWs)
Need <i>assessment</i> based on a scoring system such as ADLs	N	N	N	N
After <i>assessment</i> , <u>non-physicians</u> authorize State Plan PC	Y (RN)	Y (RN)	Y (RN)	Y (RN)
Specific criteria used for the <i>authorization</i> decision	Y (Medical necessity)	Y (Medical necessity)	Y (Medical necessity)	Y (Medical necessity)
State tracks unmet needs, that is, services (e.g., respite) or extra hours of care that are needed by clients but not currently available	N	N	N	N

Table 14, below, documents that, since 1995, NYS has offered independent providers with fiscal intermediary for participants of the consumer-directed option within the PCS program, the CDPAP. Although the majority of participants in the NYS PCS

program receive PCS through the traditional, agency-based model, the CDPAP option that allows independent providers is growing.

Table 14. NY Medicaid PCS Program Enrolled Provider Entities, 1999 & 2002-2005

	1999	2002	2003	2004	2005
Medicare certified home health agencies	N	N	N	N	N
Licensed home health & personal care agencies	Y	Y	Y	Y	Y
Centers for independent living	N	N	N	N	N
Independent providers (no agency affiliation) with fiscal intermediary	Y	Y	Y	Y	Y
Independent providers (no agency affiliation) without fiscal intermediary	N	N	N	N	N
Persons legally responsible for client (using state only money)	N	N	N	N	N
Other family members & friends, not legally responsible for client	N	N	N	N	N
Facilities such as foster care/residential/assisted living etc	N	N	N	N	N

In addition to personal care for ADL's and IADL's, NYS Medicaid PCS program services include emergency support/ respite and case management services to Medicaid state plan recipients.

Table 15. NY Medicaid State Plan PCS Services, 1999 & 2002-2005

	1999	2002	2003	2004	2005
PC services to assist directly with ADLs e.g., bathing, feeding, toileting	Y	Y	Y	Y	Y
PC services to assist directly with IADLs e.g., housekeeping, shopping, cooking	Y	Y	Y	Y	Y
Medical transportation	Y	N	N	N	N
Non-medical transportation	N	N	N	N	N
'Cuing' or monitoring	Y	N	N	N	N
Emergency support/respite	N	Y	Y	Y	Y
Animal Assistance e.g., Guide Dogs	N/A	N	N	N	N
Assistive Technology (AT)	N/A	N	N	N	N
Case management	Y	Y	Y	Y	Y
Task delegated by nurse e.g., injections	N	N	N	N	N

Location of PCS

Clients of the NYS Medicaid PCS program may utilize the PCS in their residence, at work, or in the community. As of June 2002, social service districts were advised that PCS may also be provided to Medicaid recipients who are otherwise eligible for PCS and

who are temporarily residing in emergency shelters for the homeless or other temporary housing setting in which Medicaid can be provided.

Table 16. NYS Medicaid PCS Program Delivery Sites, 1999 & 2002-2005

	1999	2002	2003	2004	2005
Client's residence	Y	Y	Y	Y	Y
Client's work site	Y	Y	Y	Y	Y
In the community, outside residence & work site	Y	Y	Y	Y	Y

Health Care Workforce and Labor Market in New York

A report by the Center for Health Workforce Studies (CHWS) reports that between 2000 and 2005 employment in home health care in NY grew by more than 14,000 jobs with the NYC region accounting for virtually all of the increase, a 46% jump in home health care jobs (CHWS, 2006). The CHWS monitors health care employment patterns as well as other indicators of the supply and demand for health workers by occupation and setting in the state and produces an annual report of the analysis and key findings. Health care workers comprise a growing share of NY's workforce and health sector employment continues to grow faster than all other employment sectors in NY (CHWS, 2006). Home health aide employment over the five-year period grew from approximately 107,000 to 115,000, a 7.1 percent increase. In NYC, between 1990 and 2005, home health care employment increased 149 percent, from 18,399 jobs in 1990 to 45,809 jobs in 2005 (CHWS, 2006). Between 2000 and 2005, home health aides increased by more than 18,000, nearly 30 percent, while those of nursing aides and attendants increased by almost 13,500 or slightly more than 30 percent (CHWS, 2006).

Labor Market and PAS Workers

In 2004, according to the UCSF PCS Center database on personal assistance workers (PAS Workers, 2007), there are an estimated 1,001,464 PAS workers in the US.

On average for all 50 States, there are 3.5 workers per 1000 people, and 141.2 workers per 1000 people with self-care difficulty. NYS ranks: first in the US for numbers of PAS workers at 147,567; second in workers per 1000 population (Maine is number one at 9.2) with 7.9; and first in number of workers per 1000 people with self-care difficulty (PAS Workers, 2007) with an estimated 322.3.

According to NYS officials, there are creative actions taken by providers to ease challenges that confront the PCS workforce in upstate NY. Even with the highest estimated numbers of workers, there are pockets of shortages. One reason stated for the shortage is the minimal pay offered. Transportation is also a big challenge for many workers. If consumers in need are located in suburbia, not on a train line or some distance from the provider, it is reportedly more difficult to receive aid. Provider agencies have taken creative approaches to the transportation challenge by using vans and hiring drivers to transport personal care attendants from one client to another as an alternative to finding public transportation or having the workers pay out of pocket for gas. Given that there are lots of competitors for other, well-paying jobs this is not always enough to keep the workforce in place.

Table 17. NYS Medicaid PCS Program Care Providers, 1999 & 2002-2005

	1999	2002	2003	2004	2005
State requires formal training for care providers	N	Y (40 hrs)	Y (40 hrs)	Y (40 hrs)	Y (40 hrs)
State requires certification of care providers	N/A	Y	Y	Y	Y
State requires supervision of care providers	Y	Y (RN)	Y (RN)	Y (RN)	Y (RN)
State allows client to hire & fire care providers	Y	Y	Y	Y	Y
State requires criminal background check for care providers	N/A	Y	Y	Y	Y
Every client has a care plan	N	Y	Y	Y	Y
Every client has a case manager	Y	Y	Y	Y	Y

Paraprofessional Training Requirements

Criminal background checks are required for care providers (Table 17), in addition to 40 hours of formal training and certification of such training to provide care. In NYS, there are three levels of certification for caregivers, each with different hours of training required for certification: First, Personal Care Attendants who are required to do 40 hours of training (also referred to as home attendants in NYC); Second, Home Health Aides, who are required to do 75 hours of training; and Third, Certified Nurses Aides, primarily employed by Certified Home Health Agencies, who are required to do 100 hours of training.

Most home health aides do not have health or pension benefits, or paid time off. The home health aide workforce primarily consists of women, many of whom are immigrants and single mothers, who have historically been underpaid. They help elderly or disabled persons who require extensive services at home, usually after they are discharged from the hospital. This post-acute care is increasingly relied upon as the amount of time that people stay in the hospital decreases. Under the direction of nursing or medical staff, home health aides provide health-related services, such as administering oral medications; monitoring pulse, temperature and respiration; helping with prescribed exercises; and helping patients move from bed, bathe, dress and groom. Personal Care Attendants, however, in addition to PCS, provide paraprofessional services such as shopping, cleaning, and laundry.

Despite the importance of the work they do, home health aides struggle financially. First, they are among the lowest paid workers in New York State, earning

only \$6-7 per hour. In order to become certified, home health aides are required to complete 75 hours of classroom training and 8 hours of supervised work in a home setting. Even with more training required, HHAs are making less per hour than Personal Care Attendants (Home Attendants). With tremendous political support from the SEIU 1199, Personal Care Attendants are now making, on average, \$10 an hour, compared to \$6-7 made by HHAs.

Workforce Development

Current LTC staffing shortages must be addressed and the work force developed to meet the anticipated need for services over the next several decades. A shortage of care providers is documented in a White Paper on the impact of an aging in NY (Prosper, 2002). Twenty agencies underscored the implications of the aging of the current workforce, the shrinking younger labor pool, and the markedly changing demographic characteristics of the state's future labor pool (Prosper, 2002). Many of the agencies reported that over half their staffs are over the age of 50 and that traditional workforce planning procedures and models do not sufficiently account for the implications of more aging workers, increasing retirements, fewer younger worker applicants, and the state's geographic population shift (greater growth in high-cost urban areas). Earnings for home care workers remain among the lowest in the service industry, according to the Bureau of Labor Statistics, yet demand for such workers is expected to explode with the aging of the baby boom generation. • Lack of adequate pay is fueling turnover rates of 40 to 60 percent annually (SEIU 1199, 2007).

Aim 2: Personal Care Service Trends in NYS

Aim 2: To examine trends in the NYS PCS program, specifically in the participants and expenditures, from 1999-2005.

To achieve Aim 2, quantitative secondary data were collected on the PCS program by the UCSF PCS Center (PCS, 2007). In addition, NYS officials provided participant numbers for years 2003-2005 on the Consumer Directed Personal Care Services Program (CDPAP).

Participants

Table 18. NYS Medicaid PCS Program Participant Summary Data, 1999-2005

	1999	2000	2001	2002	2003	2004	2005	Total '99-05
Participants								
Raw/ Overall	89,577	88,788	88,370	88,281	87,678	85,613	84,775	4,802 decrease
% of decrease in participants in PCS program		0.9 % decrease	0.5 % decrease	0.1 % decrease	0.7 % decrease	2.4 % decrease	1.0 % decrease	5.0 % decrease
CDPAP	Not available	Not available	Not available	Not available	5,717 7 % of overall PCS program	6,680 8 % of PCS program	7,505 9 % of PCP program NYC= 2,100 (28% of total CDPAP)	1,788 increase
% of increase in CDPAP participants in the PCS program	—	—	—	—	—	17 % increase	12% increase	31% increase
Total PCS participants					93,395	92,293	92,280	
Per 1,000 population	4.74	4.67	4.63	4.61	4.56	4.44	4.40	
US Average per 1,000 Population	3.08	3.30	3.28	3.78	3.94	4.15	4.31	
Rank of NY compared with other states	4	4	5	5	7	8	8	

UCSF (PCS) Center Annual Survey Data (PCS, 2007).

Table 18 reports participants in the NYS Medicaid PCS program, overall, declined steadily each year from 1999 through 2005. According to directors of provider agencies and consumer advocates, this is attributed to an effort by NYS to divert potential

PCS program participants into Medicaid managed care programs, usually those participants that are assessed for less acute needs, leaving those with higher acuity needs in the PCS program. While there was a decrease each year (less than 1 percent drop) between 2000-2003, between 2003 and 2004 there was a slightly higher decrease in participants (2.4 percent), followed by a 1 percent decrease for years 2004 to 2005, with an overall total decrease of 5 percent from years 1999-2005.

Overall, the CDPDP program participants make up only 8 percent of the total PCS program participants in NYS, although an approved option within the program for 12 years (See Table 18). Although the traditional PCS program declined over time, there has been a steady increase in the number of eligible clients in the PCS program opting to participate in the CDPAP, from 5,717 in 2003 to 7,505 in 2005. The CDPAP increased by 17 percent from 2003 to 2004 and 12 percent from 2004 to 2005, for a total 31 percent increase from years 2003-2005. The trend of increased use of the CDPAP is attributed, according to state and city officials and provider directors, as an increase in the number of elderly using what was long considered the option most utilized by younger, disabled participants. In addition, provider agencies are recommending “difficult to serve” clients, both elderly and younger disabled who fit the criteria for that category, to consider the CDPAP as an option for receiving necessary PCS.

When the total PCS program participants are combined, there has been a decline of 1,115 participants between 2003 and 2005. NYS served a higher number of participants by as much as 35 percent in 1999 when compared to the US average per 1000 population (see Table 18). A steady drop off in difference between NYS and the US

average follows for subsequent years as the NYS PCS program went from a rank of 4 among states in participants per 1000 population in 1999, declining to a rank of 8 in 2005.

In addition, the New York City Department of Social Services Human Resources Administration Office of Program Reporting, Analysis and Accounting provides a monthly fact sheet available on-line (see Table 19). Results of one month (January) from 1999-2005 are shown below to document trends in the data for NYC over the same time period as the overall state data above.

Table 19. New York City HRA Medicaid PCS & LTHHP Fact Sheet Data

Total Home Attendant Participants (PCS program)		Long Term Home Health Care Participants	
Month/ Year	Participants	Month/ Year	Participants
January 1999	45,224	January 1999	8,555
January 2000	46,880	January 2000	8,318
January 2001	46,467	January 2001	7,665
January 2002	46,548	January 2002	8,834
January 2003	46,037	January 2003	10,246
January 2004	46,732	January 2004	12,516
January 2005	45,791	January 2005	13,284

HRA Fact Sheets: Accessed at: http://www.nyc.gov/html/hra/html/hra_facts/hra_facts.shtml for January 2005.

Participant numbers confirm a relative decrease in participants in the PCS program in NYC, following the trend for the state overall, at a time when there is a steady increase in participants enrolled in the Lombardi Waiver Program, and in the Medicaid Managed Care Programs, an alternative available option for PCS. In 2005, the last year of the study, NYC had 2,100 participants enrolled in the CDPAP, 28 percent of the total 7,505 CDPAP participants for that year of the program. The remaining 72 percent of participants are spread out over the other 58 counties, confirming the increased use of the CDPAP option for those participants in rural areas not easily served by traditional provider agencies.

Expenditures

Expenditures for the NYS Medicaid PCS program, however, continue to rise demonstrating that, although participants are declining in number, the program expenditures continued to increase from \$1.46 billion in 1999 to \$2 billion in 2005. NY spends more than double on PCS per participant compared to the national average (see Table 20 below) (\$24,078 per participant compared to \$9,773 for the US in 2005).

Table 20. NYS Medicaid PCS Program Expenditure Summary Data, 1999-2005

	1999	2000	2001	2002	2003	2004	2005
Expenditures							
Raw	\$1,464,026,040	\$1,520,556,019	\$1,571,618,449	\$1,589,924,504	\$1,765,670,979	\$1,930,721,116	\$2,041,180,234
Per capita	\$77.53	\$80.04	\$82.39	\$83.09	\$91.83	\$100.14	\$106.01
US Average per capita	23.8	25.95	29.62	29.74	35.47	38.61	41.88
NY rank per capita	1	1	1	1	1	1	1
Per participant	\$16,344	\$17,126	\$17,785	\$18,010	\$20,138	\$22,552	\$24,078
CPI-adjusted (2005)	\$1,716,232,207	\$1,724,533,046	\$1,733,128,645	\$1,726,026,991	\$1,874,513,711	\$1,996,134,642	\$2,041,180,234
US average per participant	\$7,727	\$7,876	\$9,031	\$7,872	\$9,008	\$9,314	\$9,773
NY rank per participant	3	3	3	3	2	1	1

Adjusting for inflation, overall expenditures for the PCS program increased by 139 percent from 1999-2005. Expenditures increased most with an 11 percent rise between 2002 and 2003, followed by a 9 percent increase between 2003 and 2004 and a 6 percent increase between 2004 and 2005. Per participant expenditures for the NYS PCS program are, at least, twice as high as the US average per participant from 1999-2003 (Table 20), rising to almost three times as much by 2004 and 2005.

As the number of participants remains stable or decreases, expenditures for the PCS program continue to increase, one justification for the referral of potential enrollees to less costly Medicaid Managed programs as a cost containment measure in NY. From

1999-2002, NYS ranked 3rd in per participant expenditures compared to the US average, rising to the rank of 1st for 2004 and 2005.

Aim 3: Stakeholder Groups and Competing Logics

Aim 3: To examine how competing logics of key stakeholders are generating change in the NY PCS program.

Interviews with study participants took place by the investigator doing site visits to NYS department facilities, provider agencies, and the offices of unions and consumer group representatives. The views expressed by study participants are a reflection of the individuals interviewed and their unique experience of the PCS program taking into account the history, culture, and political environment of NYS. Below is a brief description of each of the four groups that participated in the study and followed by competing logics expressed and analyzed from interviews with representatives from each of the stakeholder groups.

Stakeholder Groups

The NYS PCS Program (Agency)

In 1995-1996, the Department of Social Services (DSS), previously responsible for the PCS program, was absorbed into the DOH resulting in the staff responsible for the Medicaid PCS program to also be absorbed. And while the staff familiar with the PCS program carried over with that absorption, structural decentralization of the PCS program accounts for administration to vary dramatically across districts, having more of an impact than any one central office (the OMM) can. The OMM designates a liaison from the OMM to meet in person with formal CASA (DSS) representative groups in NYS regularly. However, communication from the OMM to DSS offices in each county, and

to HRA in NYC, is primarily through the use of administrative directives, written communication delivered electronically.

Eight State and City program officials associated with the PCS program were interviewed for this study and appeared to be extremely knowledgeable about the overall organizational structure of LTC programs at the state level and especially, because of their role, the PCS program. Some State officials had been responsible for the PCS program from its inception and were generously informative on the institutional history of the program in addition to program contents. Participants interviewed from the OHSM represent the Divisions of Health Care Financing and Division of Home and Community Based Care, and the Bureaus of LTC Reimbursement and Home Care Surveillance and Quality. Participants from OMM represented the LTC Division. Overall, each of the participants interviewed expressed confidence in their own knowledge and experience managing and overseeing the PCS program. Other officials in NYC, representing HRA, were included to have representation of the location where the majority of participants in the PCS program are served. There are differences in the program depending on where one is served.

Within the PCS program, there appears to be a distinct difference between NYC (the five boroughs) and the rest of the state. Understanding the demographics that approximately 80 percent of the costs and participants of the PCS program are in NYC makes clear that program developments within NYC affect the program more significantly than those in other regions of the state. Program officials report that the inter-relationship of services takes into account the characteristics and needs of both the upstate and NYC populations for guiding decisions about the allocation of resources and

the development of services. However, there is also a reported historical culture of “entitlement” regarding services provided (primarily hours of care) that empowers a wide variety of individuals and organizations to have an impact on the program. The involvement of politicians, unions, and consumer advocacy organizations advocating for client services and workforce benefits appears to be unique to NYC and accounts for much of the distinct developments in the PCS program for NY to be dependent on where you live.

Expecting a turnover in experienced staff in the near future as many long-term NYS employees retire, there is a concerted effort by the DOH senior staff to mentor junior staff to address discrepancies in the PCS program based on location. Key state officials expressed a commitment to sharing their knowledge on management of the PCS program with junior administrators being groomed to fill leadership positions within the organization. This continuity of program management was a major goal expressed most strongly by DOH staff that has been involved with the PCS program since its inception in the early 1980s. This transference of knowledge appears to influence the views and competing logics being carried over from experienced state officials to those they mentor that are following them in overseeing the PCS program.

PCS Provider Agencies

According to state officials there are approximately 950 licensed provider agencies providing PCS in NYS. Many of these are small in comparison to the 70 licensed agencies in NYC serving approximately 90 contracts for the PCS program in the five boroughs. HRA officials report that each of the contracts has 400-1200 participant slots. This works out to NYC providing approximately 80 percent of those enrolled in the NYS

PCS program. Each provider has a contract with NYC via HRA with a negotiated rate, approved by the state, and bills for hours of care provided. Every six years HRA puts out a request for proposals (RFP) for providers to bid on and the process of negotiations for eligible agencies is repeated. HRA reviews all the proposals, visits the facilities, and documents that agencies actually do all that they say they do. Typically, according to HRA officials, the larger agencies with experience do well, but it is not a given that they will be awarded a new contract based on this alone, as the process of RFP is the same for each agency. While there used to be a minimum contract size of 200 participants, that has been increased to a minimum of 400 (with a maximum of 1200), eliminating the smaller agencies from the application process

In NYC, the breakdown for not-for-profit vs. proprietary agencies providing PCS is, approximately, 70 percent not-for-profit and 30 percent proprietary. In addition, three agencies are contracted in NYC to provide PCS to *difficult to serve* clients, one proprietary and two not-for-profit, and are awarded a higher, negotiated rate to do this. Also, unlike more rural areas, agencies contracted with HRA meet the needs of their clients by having staff that speak the various languages required to meet the needs of NYC's culturally diverse clientele served.

Two major associations serve homecare providers in NY: the Home Care Providers, made up of primarily licensed home health agencies; and the Home Care Associations, made up of, primarily, the CHHAs. Many agencies have several programs and are not limited to providing PCS alone, and some offer in-house training for homecare certification programs including those for home attendants (40 hours), home health aides (75 hours), and certified nurse's aides (100 hours). Others provide training opportunity

information and referral for potential employees to a list of over 100 training programs available throughout NYC and State. Two agencies are responsible for the majority of the approximately 2,100 CDPAP participants in NYC, while the remaining approximately 5,000 CDPAP participants are served by smaller fiduciary provider agencies throughout NYS.

Directors of provider agencies interviewed for the study were, like the state and city officials interviewed, also very knowledgeable regarding the NYS PCS program. Most of those interviewed had been in their positions for over 5 years, with some as long as 13. They reported a good working relationship with DOH program officials and expressed confidence that their concerns and opinions were heard and considered. Five directors were interviewed for this study. One was director of a proprietary agency while four were directors of not-for profit agencies providing PCS. Two were directors of agencies serving CDPAP clients, one in NYC and one in northern NYS.

Health Care Unions

The majority of homecare workers providing PCS in NYS are members of Service Employees International Union (SEIU) 1199. This is true for NYS overall and, especially, NYC. Although Communication Workers of America (CWA) has some hospitals in the upstate Buffalo area and the Civil Service Employees Association (CSEA) has a couple of hospitals on Long Island, ninety-nine percent of homecare workers in NYS are unionized with SEIU 1199 (2007). One union official with extensive experience with SEIU 1199 was interviewed for this study.

The Homecare Division of 1199 SEIU in NYS is made up of approximately 70,000 home attendants, housekeepers and home health aides with the majority of these

being home attendants (SEIU 1199, 2007). There are a small number of proprietary provider agencies that are non-union, though this is shifting. Recently, one of the largest proprietary agencies providing PCS signed a contract with SEIU 1199.

In addition to homecare workers, SEIU 1199 represents a number of occupational workers including: registered nurses; hospital workers; clinic workers; and drug store workers (SEIU 1199, 2007). Homecare workers in NY are organized within the SEIU 1199 internal structure along “health systems” lines, designed primarily for collective bargaining purposes to align with homecare agencies. There is a long history of union representation of workers in NYC.

Pharmacists started the original 1199 in NYC in 1932 and, beginning in 1959, this local New York 1199 union expanded out to hospitals in the 1960s with an injunction with the civil rights movement (SEIU 1199, 2007). They then became the Health Care Workers Union in NY, later affiliating with the Service Employees International Union (SEIU 1199, 2007). Currently, the bulk of the homecare workers affiliated with SEIU 1199 are in the five boroughs of NYC. They are the largest union in the city, the most powerful, and incredibly politically organized. According to union officials, in NYC, 75 percent of union members and 90 percent of the home workers voluntarily give money each month to a political action fund, well above the national average voluntary contribution of 10-15 percent. The homecare workers in NYC are very politically engaged, and the Homecare Division of SEIU is the largest and fastest growing division for the union nationally (SEIU 1199, 2007).

In 2002, New York legislators passed a controversial \$1.8 billion health care package, the *Living Wage Bill*, endorsed by Dennis Rivera, leader of SEIU 1199, that

legislated living wage increases for some of the state's lowest-paid healthcare workers. Highly criticized for its political overtones and severe effect on the morale of healthcare workers in upstate New York not covered by union representation, the legislation provided disproportionately to NYC, where workers are far more likely to be unionized. For example, while the bill allocated \$696 million for hospital workers and \$475 million for nursing homes over three years, personal-care workers received \$964 million over the following four years. Once the health care bill was signed into law, Dennis Rivera endorsed Governor Pataki in his re-election bid for governor (SEIU 1199, 2007).

Because of the *Living Wage Bill*, home attendants make more per hour than home health aides, whose certification requires 75 hours vs. the 40-hour training required to be certified as a home attendant. Home health aide funding is different than that of the home attendant, which follows the 50 percent Federal, 40 percent State, and 10 percent City formula. The funding stream for home health aides, however, is based on a bidding process through the Certified Home Health Agencies, (CHHAs). Hospitals or other large agencies put out bids for home health aide coverage. A large provider such as VNS, for example, would compete for the bidding contract and then sub-contract with a smaller agency to fulfill the contract. The bidding contract process affects the bottom line for agencies looking to make a profit and thus contributes to the low wages (\$6-7 an hour, on average) for home health aides' compensation, considerably lower than the \$10 average for home attendants.

A recent Federal case on the wages of home attendants was heard by the Justices on April 16, 2007 (Greenhouse, 2007) and is another example of union support in advocating for the rights of homecare workers. The case highlighted the need for

clarification on the role of home attendants as to whether they are to be defined as *companions* or whether they are entitled to overtime pay when working overtime to serve clients in need. The lawsuit dealt with the Fair Labor Standards Act of 1974, when Congress extended minimum wage and overtime coverage to household workers like maids and cooks but said that baby sitters and “companions” for the elderly and infirm would be exempt. A ruling in favor of the sole home attendant who sued one Long Island, NY agency for overtime could have affected thousands of workers and cost the home care industry millions of dollars in unpaid overtime. Ms. Coke, the home care attendant in the case, was backed by SEIU (the Chicago Division of SEIU and not NY, which would have been too politically charged after advocating and winning the *Living Wage Bill*) stating that a victory for her could mean larger paychecks for hundreds of thousands of home care attendants in the US, many of whom live in poverty (Greenhouse, 2007). Arguments in the case were heard by the Supreme Court on April 16, 2007 and, on June 11, the Supreme Court ruled that the nation's home healthcare workers are not entitled to minimum wages or overtime pay under •federal law, even if they work for private employers (Savage, 2007).

SEIU 1199 is a strong political action group. As one union official explained,

“There are other 1199s in other states, but when I talk about 1199 or anyone in New York talks about 1199, we’re talking about the New York Local. Seventy-five percent of 1199 voluntarily gives money towards political action. I think your average, nationally for a union, is closer to 10 or 15 percent. They’re very engaged. Very, very engaged. In the homecare division, it’s closer...it’s over 90 percent give voluntarily to the political action fund, which is the largest political action fund in the country.”

Consumer advocacy organizations aim to represent the rights and needs of consumers as strongly as unions represent homecare workers and make up the fourth group participating in the study.

Consumer Advocacy Organizations

Consumer advocacy group representatives interviewed for the study were also quite knowledgeable regarding the PCS program. Six participated in this study, providing a window into the history and support for PCS in NYS. Interestingly, a few of those interviewed who are now with research institutes that study LTC had, at one point, been administrators of the PCS program at HRA and were extremely knowledgeable regarding the structure of the program, having been responsible for it at an earlier time in their career.

The Center for Independent Living in NY (CIDNY) is one of the most active organizations advocating for consumer rights and represents well what an organization dedicated to consumer advocacy does. Located in NYC, where the majority of the people with disabilities in NYS live, it is extremely dependent on state policy to carry out its mission in supporting the disabled of NYS to live as independently as possible, and focuses heavily on advocacy and policy development at the state level.

The Center has been in existence for nearly 30 years, was the first independent living center in NYS, and has helped to found other independent living centers in NY and the US. The Center came into a landscape in the 1970s, at a time where there was very little to support and sustain community living for people with disabilities. At that time, most disabled people were living in institutions or with families but without much in the way of community resources. There was virtually no effective transportation at that time

for the disabled, little in the way of employment, and a healthcare system that relied on institutionalization. Attitudinal barriers during that time in history assumed that if you had a disability you were an object – you were objectified and you were dependent. Homelessness was rampant among people with disabilities and little was being done in government to enable people to be independent altogether. Since the Center was founded, it has played an important role in improving access to transportation and to voting, in addition to being instrumental in improving access to a social service safety net for people with disabilities.

Although there are other cross-disability organizations in NYS, the CIDNY serves the largest number of people with disabilities with clients of all ages, serving approximately 15,000 in NYC in 2005, with a budget of a little more than two million. Typically, the Center brings in people who come because they've encountered a roadblock of some kind, though they also have an aggressive outreach program. They assist people in getting connected to services, care, rehabilitation, and employment, and they do community education for people with disabilities by developing workshops on housing, health care, voter rights, and other topics. Housing and healthcare are, by one official's report, the most in demand. The Center responds by taking those workshops on the road, going to agencies that serve people with disabilities and to others that have a population of staff people with disabilities, themselves. By obtaining access to a classroom or a meeting room where they conduct workshops to directly teach people how to help themselves, they educate people with disabilities where they're at by setting up tables and doing on-site counseling.

The director of the CIL in New York interacts directly with the Governor's Office and with the heads of agencies at Medicaid, education, and at housing. The CIL staff appears to be very passionate about what they do in bringing their own experience into focusing on people throughout their work/life cycle and their employment issues. They help people who are faced with developing skills to enter the work force, those trying to obtain a higher education because that means so much in terms of job opportunity and income for people with disabilities. It has a big effect. They reportedly act on the premise that the more education you have the more wage you can command and the more movement in the workforce you can have. They also work with people who have a disability, have been out of the workforce, and who are trying to figure out how to reenter. They have people on staff that have made that leap, people who work with youth and with adults around workforce issues who have all been out of the workforce and had to come back in, themselves. So they can do, in effect, peer counseling as well as have specific expertise and knowledge and be in a position to access services.

The CIL have federal, state, and city funding, in addition to foundation dollars and private donors. Everyone who is senior staff works on development. Managers come up with ideas for projects based on the experiences they have working in education, policy, advocacy, and direct service. The board does donor solicitation. The director, staff, and board are all engaged in raising funds for the agency.

Other Advocacy Organizations

There are other agencies in NY that are disability specific. For example, there's a strong multiple sclerosis organization, the MS Society, serving people with MS though they don't do as much public policy work or advocacy work as the CIDNY. Likewise, the MS Society focuses a lot of resources on research, which CIDNY does not. They do a lot

of disease specific education, and much less with respect to opening the community to people with MS. CIDNY, however, has a close working relationship with the MS Society and other organizations in NYS. There is a statewide organization of voluntary health organizations such as the American Cancer Society, the Multiple Sclerosis Society, CIDNY, and approximately 50 groups altogether, working together as an entity called New Yorkers for Accessible Health Coverage that has been in place since the early 1990s.

The New Yorkers for Accessible Health Coverage has been responsible for many law changes in NYS. For example, the association has been responsible for passage of open enrollment in community rating laws that ensure that people with disabilities are guaranteed to be able to buy their own insurance coverage and not to pay more than anyone else who buys insurance coverage as an individual or a family. They also take credit for the nation's first Managed Care Bill of Rights that set the stage for other state laws. They created the first compliance plan for Medicaid Health plans and participated in broader coalitions of all social service agencies relative to housing and healthcare. At the city level, CIDNY participates in citywide bodies related to education and employment, and at a state level, CIDNY participates in the Statewide Association of Independent Living Centers. The current director of CIDNY is the vice president of the Statewide Association of Independent Living Centers and is extremely active in collaboration with other agencies throughout the state in having a strong united front at the state level to bring attention and commitment to people with disabilities and the organizations that serve them. Issues of most concern to advocacy organizations are shared, along with other key stakeholder group representatives' concerns, in detail below.

Competing Logics

Four major stakeholder groups play a significant role in influencing change within the NY PCS program: State and City officials (Agency); PCS provider agencies; unions; and consumer disability advocacy organizations. Representatives from each group openly shared their views on the NY PCS program during the interview process for the study.

Table 21 illustrates a summary of where study participants agreed on aspects of the PCS program, expressing *no problem*, and key areas that reflect expressed concern, indicating areas where competing logics appear to be influencing the PCS program and by whom.

Table 21. Competing Views of Study Participants on: Planning; Access; Clients; Fraud; and PCS Budget.

	State & City Officials	Directors of Provider Agencies	Union Officials	Consumer Advocates
Olmstead Planning	No Problem	No Problem	No Problem	YES
Access to Services	No Problem	No Problem	No Problem	YES
Consumer Direction	No Problem	No Problem	No Problem	YES
Consumer Fraud	YES	No Problem	No Problem	No Problem
PCS Budget	No Problem	YES	YES	YES

The primary areas of concern voiced by study participants may be summed up by: 1) Olmstead Planning; 2) Access to Services; 3) Consumer Direction; 4) Consumer Fraud; and 5) the PCS Budget. While consumer fraud concerns dominated the expressed beliefs from state and city officials as reason for barriers to the expanding consumer-directed model (CDPAP) vs. the traditional, agency-based model, directors of agencies were most concerned about how to manage diminishing budgets to provide PCS, manage workers, and remain competitive as provider agencies. Union officials expressed, understandably, a strong desire to see an increase in wages and benefits for those the workers they represented and were mainly focused on this issue, though, interestingly, only on agency-based workers and not currently invested in unionizing independent providers. Consumer

advocates expressed strong beliefs regarding four of the five key areas of concern and were the most outspoken advocates for both consumers and workers.

While the findings on this case study of the NYS PCS program document a well-established program with agreement on many aspects of its operations, competing views from the four participating groups studied were made evident from interviews, primarily in five areas, and held by representatives of each of the four participant groups. Each of the five analyzed areas where competing logics were identified in Table 22 is further described below. Response to the Olmstead Decision and Strategic Planning

In response to the Olmstead decision, there has been an effort by NYS to address this issue in relation to the LTC system and the requirements of CMS although, as yet, there is no formal plan. The Coalition to Implement Olmstead in New York (CTIONY), a statewide organization formed by consumers, advocates, and service providers, was formed in October of 1999 to advocate for the implementation of Olmstead in NY. Since the historic Supreme Court decision, the CTIONY has advocated for NY legislation (A.9913-B/S.7342-A) designed to begin the Olmstead process. On September 17, 2002, Governor George E. Pataki signed the *Most Integrated Setting* into law. In February 2003, the CTIONY highlighted a number of issues and recommendations for NY in a policy paper (CTIONY, 2003) for the process of NY creating an Olmstead plan. Recommendations for a comprehensive, effectively working NY Olmstead Plan address a process for creating a plan including its components and the major issues the proposed plan must address.

Most Integrated Setting Coordinating Council

As called for in the new law, in early 2004, Governor Pataki announced the establishment of the Most Integrated Setting Coordinating Council (MISCC, 2004) to explore and recommend ways to ensure that New Yorkers with disabilities receive services in the most integrated settings appropriate to their individual needs. The Council's actions are guided by the principles set forth under the Olmstead decision to empower individuals with disabilities to live more independently. NYS Agency Council Members included, among others: the Office of Mental Health; The DOH, The State office for Aging; the Office of Mental Retardation and Developmental Disabilities; Education Department; Office of Alcoholism and Substance Abuse Services; Division of Housing and Community Renewal; Department of Transportation; Office of Children and Family Services; Office of the Advocate for Persons with Disabilities; and the Commission on Quality Care for the Mentally Disabled.

In 2004, following the creation of the MISCC, the council met in May, June, July, September, and October. On November 9, 2004, Governor Pataki signed "Law Creating Greater Opportunities for New Yorkers with Disabilities to Live in Their Communities" (MISCC, 2004), which remains the most current Olmstead plan for New York. As of 2007, New York State still did not have an "Olmstead Plan" yet had developed the comprehensive working plan described above.

There is consensual agreement among study participant groups that the decentralized distribution of authority among the agencies and within different units of the DOH makes the establishment of program-wide priorities, coordination, and oversight in addressing Olmstead difficult in the PCS program. Consumer advocates believe that

this de-centralized governance is partly responsible for thwarting the development of a comprehensive effort toward consumer direction in PCS. Responses from state and city officials to questions regarding Olmstead were consistently expressed as, “no problem”. In their estimation, NY did a good job addressing Olmstead issues citing the generous hours provided to PCS consumers and the closure of nursing homes over the last decade. One city official did not appear to comprehend what I was referring to when inquiring about the “Olmstead Decision” during the interview. Other state and city officials dismissed any concerns as minimal. Directors of provider agencies and union officials also stated that NY, in their estimation, did a good job of addressing Olmstead issues. Consumer advocates, however, were extremely critical in how little NY has done to address Olmstead. As one director of a consumer advocacy organization articulated,

“Olmstead isn’t just about the move of people from nursing homes to their own home in terms of getting them in an ambulance and physically transporting them to an apartment. It is about housing policies that facilitate or preclude community re-entry. It is about social service policies that don’t include home visits or that place enormous barriers in the way of people applying and recertifying for retaining public benefits. It has to do with the commitment of resources to community-based infrastructure and HCBS, not merely the existence of a program that provides PCS.”

State officials, directors of agencies, and union officials appeared to be varied in their awareness of the Olmstead ruling and how it was being implemented in NY. Consumer advocates, however, were most articulate in pointing out what was missing, most notably consumer direction as a first component in all PCS choices. Currently, without an Olmstead Plan in place for NYS, participants report a lack of agreement about what should take priority in serving eligible PCS program clients in NY. There are

counties without any ADA compliance plans, according to one consumer advocate interviewed, and others that do not offer licensed PCS at all. Access to services was another key area of concern to advocates.

Accessing Personal Care Services

The PCS program is decentralized in administration. It is most strongly administered and influenced at the county level first and foremost, more than from any centralized state control. This is most evident in local District Social Service Agencies. Local District Social Service Agencies are the gatekeepers of participant eligibility to both the LTHHCP and the PCS program, and provide eligibility determination and recommendations for appropriate services, including the CDPAP, when appropriate and/or requested. In NYC, however, consumers access Medicaid-funded PCS from one of the Home Care Services Program's nine local Community Alternative Systems Agencies (CASA). A nursing and social assessment is conducted in the client's home and a plan of care is developed to meet the client's specific needs. The Home Care Services Program preauthorizes the weekly number of hours to be provided based on the determined level of need. When both the plan of care and Medicaid coverage are in place, the client is assigned to a contracted provider within the five boroughs. Each client has a caseworker assigned to be responsible for ongoing oversight of the case, including service reauthorization at appropriate intervals.

The statewide CASAs, in partnership with each county DSS, function primarily to determine the appropriateness and necessity for Medicaid LTC services and develop suitable plans for PCS. As such, these DSS and CASAs are the primary gatekeepers to PCS in NY and, although varied in location and service delivery, do come together. The

LTC CASA Association is made up of approximately 30 counties and the 9 CASAs in NYC (1 in the Bronx, 3 in Brooklyn, two in each of Manhattan and Queens borough offices, and one on Staten Island). The association meets every other month and is joined at that time by a staff liaison from the OMM. Local social services districts administrate both programs (the PCS program (including the CDPAP), and the LTHHCP) in all counties except NYC, where the Human Resources Administration (HRA) manages the program in a cost-neutral fashion for the five boroughs.

State and city officials and directors of provider agencies see no problems in current practices of consumer's access to services. Likewise, union officials did not voice this as an area of concern, either. Consumer advocates, again, were the participants who expressed the need for better access to PCS by those in need. They were also the most pleased with the following plans for development of better access to services outlined below by state and city officials.

Informed Choice

Currently, the CASAs, in partnership with each county DSS, function primarily to determine the appropriateness and necessity for Medicaid LTC services and develop suitable plans for PCS. Likewise, the CASAs in NYC, in partnership with the HRA, functions the same. Recently NYS has announced plans for the development of a local Point of Entry (POE) that will provide a consumer-centered entry point for LTC services across the state. POE will be accessible to all individuals who may need assistance with the LTC needs regardless of age or payment source. Many of the participants in this study referred to the POE concept as "no wrong door".

Introduction of Single Point of Entry for New York State

In local communities across NYS, LTC services are supported by numerous funding streams, administered by multiple agencies and have complex, fragmented, and often duplicative intake, assessment and eligibility functions. Accessing services is difficult for persons who qualify for publicly funded support and for those who can pay privately, often leading to premature institutional placement. Recognizing this as a problem for NYS, in May 2006, non-competitive Requests For Application (RFA) for the development of POE were sent out by the NYS Office for the Aging (NYSOFA) and the DOH to county administrators and managers of area agency on aging (AAAs) and local departments of social services commissioners. The NYSOFA and the DOH will jointly consider RFAs that support the development of a local POE for accessing LTC services, established at the county level and operating throughout the State. Each POE will provide a consumer-centered entry point for information about LTC and linkages to services that assist individuals of all ages with LTC needs. POE will be available to serve individuals who require LTC, their caregivers, and those planning for future LTC needs, whether it is anticipated that public or private sources of payment will be used. POE will also serve as a resource for LTC professionals and others who provide LTC services to the elderly and people with physical disabilities of all ages.

Looking forward, NYSOFA and DOH will share oversight in the development and implementation of a POE in every county in NYS that will be implemented in two phases. Phase One will establish local POE to begin operation, and Phase Two will transition POEs to fully operational status, to occur in conjunction with NYS LTC restructuring initiatives (Bachrach, 2006). As an essential component of restructuring

LTC in NYS, the NYSOFA and the DOH will jointly consider applications from county governments across the state and NYC. Applicants will commit to work with local partners to provide consumers and their caregivers with comprehensive and unbiased information and assistance on all available LTC services and programs, consistent with Olmstead's mandate to provide consumer-direction.

Consumer-Direction in the Personal Care Services Program

Consumer directed care in the PCS arena refers to a range of practices designed to place the consumer in the "driver's seat" in regard to the receipt of PCS services.

Consumer direction can range from consumer development in the individual care plan of PCS with the traditional, agency-based model to the hiring and firing and training of personal care assistants available to consumers who receive PCS in the CDPAP model.

State and City Official Response to Consumer-Direction and the CDPAP

Requiring that CDPAP services be provided across NYS in 1995 was one of the first major accomplishments of the Pataki administration according to the Consumer Directed Personal Assistance Association of New York State (CDPAANY). The CDPAP finally gave consumers the authority to control their PCS, and allowed self-directing individuals to receive more cost-effective social model community supports rather than being forced to use more restrictive and costly medical model services. The relationship between the CDPAANY and the DOH, however, has not been smooth sailing, though spokesmen from both sides report that communication remains open and there is a willingness to respond to issues as they arise. The CDPAANY, representing consumers and providers, reports a continual "push back" on expansion of the CDPAP from state and city officials. The CDPAP is expanding yet its policies and procedures are

unclear to many counties and certainly not consistent throughout NY. Advocates for expansion of the CDPAP provided the communication on policy directives from the DOH OMM below to demonstrate that, while the traditional, agency-based PCS program is well known, the CDPAP is not. Member organizations of the CDPAANYs would like to see that change and provided an example of communication between the agency responsible for the program and those counties making efforts to expand below.

The DOH OMM sends periodic notices through its general information system (GIS), alerting local commissioners and Medicaid directors of policy directives. The purpose of a GIS on April 7, 2004, for example, was to clarify the scope of services that an aide in the CDPAP may provide. The scope of services that an aide may provide includes all services provided by a personal care services aide, home health aide, registered nurse or licensed practical nurse. Specifically, a CDPAP aide is able to provide nursing services because the Education Law specifically exempts CDPAP aides from having to be licensed under Article 139 of the NYS Education law, otherwise known as the Nurse Practice Act.

In March 2006, the DOH responded to a collection of questions from a variety of local social service districts regarding the CDPAP who were unclear on these issues. The purpose of the memorandum sent in response from the OMM to all local district commissioners was to transmit a compilation of answers to questions submitted by the local social service districts, fiscal intermediaries and CDPAP consumers regarding the program. In April 2006, the CDPAANYs sent a letter in return to the NYS DOH, Division of Consumer and Local Districts Relations, Bureau of LTC to request that the DOH recognize its responsibility to promulgate actual regulations and work with the

CDPAANYS and the disability community to create regulations that effectively support the CDPAP and its availability for consumer access as an option.

The letter from the CDPAANYS, as an association, to the DOH in response to the March 2006 memorandum, recognized that, while the DOH has a much better understanding of the regulatory requirements being set forth by the federal government, it is entrenched in the medical model and the department's staff are far less able to identify approaches to meeting the regulatory requirements that maintain the integrity of the CDPAP. The CDPAANYS included an attached paper providing detailed responses and expansion of the issues raised in the memorandum sent by the DOH in March 2006. Ongoing meetings with CDPAANYS and the DOH staff continue while the CDPAP remains "under the radar" as an option to many consumers who might choose the program, according to representatives from the CDPAANYS.

When questioned about Olmstead activity in NY, program officials consistently responded that NYS was, "compliant and a leader in consumer direction for the country", often citing the CDPAP as an example. They were also consistent, however, in their reservations about the CDPAP expanding without better quality oversight of the program being put into place to counter potential fraud, their main concern. Officials relayed that the CDPAP referrals currently being made are most often for those described in the *difficult to serve* category. When questioned further, it was explained that the CDPAP, in their opinion, was most appropriate for the younger, disabled participant who is fully capable of self-direction and for participants in rural areas (both younger disabled and elderly) who are in geographic areas that agency-based models find difficult to provide services to, whether because of limited assessed hours of care allotted or transportation

difficulties for an assigned provider. And, while directors of provider agencies expressed similar views, consumer advocacy organizations, understandably, feel differently, accounting for competing views for consumer direction in this category, as mandated by Olmstead.

One thing that distinguishes grass roots disability rights group from other consumer advocacy organizations is their willingness in using all the advocacy tools that are available, including direct action. Direct action, according to the director of one such organization in NY, meant, for example, collaboration with legislatures on policy issues, but also civil disobedience, if necessary, to make a point. Some directors of advocacy agencies have more than one role in the PCS field. There are directors of provider agencies that are consumers of PCS themselves, and others who are directors of both an advocacy organization and provider of PCS. One director with dual roles from upstate NY explains,

“Our center acts as an intermediary for clients in the CDPAP [fiduciary agency]. It has grown to the point where the traditional [agency-based] PCS providers feel threatened by the program. My county’s peculiar in that it’s opposed to the whole statewide issue of PCS programs altogether. Monroe County doesn’t have any contracts for standard PCS. They use certified home health services, instead. What you’ll find in NY is that the application, the use of long-term care services, varies dramatically from county to county. So there isn’t a really uniform application of how we use services. What you’ll find is that PCS are favored downstate. In NYC, roughly 90 percent of the people are in PCS programs and approximately 10 percent get certified home health. And when you come upstate, it flips to the opposite, where 90 percent are in certified home health and only about 10 percent are in PCS programs.”

Directors of provider agencies who are involved in advocacy, either as a consumer of PCS themselves or as leaders in the advocacy community, appear quite knowledgeable of the policy issues involved with PCS and with the allocation of funding

in NY for the advancement of HCBS. As one director summed up their understanding of where NY stands in this regard,

“There have been a lot of attacks on the PCS program and I think it’s very much misunderstood. A lot of policy people in NY will say that we spend more on the PCS program than any other state, and that is true. What they don’t tend to look at is where other states also spend money. If you look at our LTC system in the aggregate, a lot of other states do PCS through a waiver. And the money from the waiver slots...not the personal care slot ... because NY does not have, you know, any significant waiver that would serve people with significant disability, so you have to add those rows together to get the total spending. And when you do that, what you find is the number shifted a bit, but we’re still, you know, two thirds of our spending for people with physical disabilities and the elderly is institutional nursing facility money as opposed to HCBS.”

Representatives from consumer advocacy organizations articulated their concern for lack of consumer-direction in NY and an increased need for awareness of the CDPAP as part of a package of LTC and PCS that met the mandate of Olmstead and consistently made access to such services available to all in need of PCS.

Consumer Organizations Advocate for Expansion of the CDPAP

According to consumer advocates interviewed, in NYS, the CDPAP offers consumers important components for independence not present in other programs. In NYC, advocates initiated a dialogue with the city about the need and desirability for an expansion of the CDPAP, widely recognizing that the CDPAP is an appropriate model for people with disabilities and for seniors. Key among these is the ability to select one’s own worker, what times they will come to the consumer’s home to provide PCS and, the ability of the consumer to teach the worker how to do what the consumer wants them to do. As one CIL director stated,

“The sense that you are an actor in your own life and in control in a situation where you are otherwise often infantilized and not respected and not treated with dignity”.

Important to note is that the CIDNY was the agency that worked with the HRA in NYC in the 1970s to help develop one of the first home attendant programs in the city, CIDNY-ILS, for Independent Living Service. Created as a home attendant program, it would focus on being a model that was “disability sensitive” and not a medical model. Unfortunately, according to one CIL director, as the program evolved, the mechanisms in place in NYC didn’t foster referrals to the agency that sustained that mission. In other words, the agency was created with the focus on people with disabilities of all ages, and yet the NYC system didn’t encourage a pattern of referral of people with disabilities of all ages to the agency so they’re now scattered among many different agencies. CIDNY-ILS is still in place and still has a contract with HRA as its own corporation, only sharing the name yet separate from CIDNY, with its own license. Because of this history, consumer advocates strongly believe that more can be done for consumer direction in the PCS program.

Consumer advocates assert that NYC officials are in denial about there being reasonable accommodation issues for people with disabilities, stating that many county social services districts in NY don’t have effective planning in place for people to access services in the community. This situation tends to foster a climate where institutionalization is the only answer. One consumer advocacy organization director, aware of the situation throughout the state, explained that, while it is possible for someone to get PCS and move from a nursing home into the community, navigating the resources by themselves is very difficult because it is an inordinately complex process.

The Unions are currently more concerned with organizing and expanding home care attendant membership outside of NYC than on the independent workers used by consumers in the CDPAP in NYC and elsewhere. Advocates for the expansion of the CDPAP, while appearing supportive to all caregivers, appear to be frustrated with the unions singular efforts to organize workers within the traditional, agency-based PCS program, possibly at the cost of hours served for those in the CDPAP. Thus, while there are convergent concerns of both advocacy organizations and unions, there are questions, also. As one director stated,

“My role is in defending the PCS program here in NY; primarily the CDPAP. My question to the union is... How does the union feel about supporting the right of people with disabilities to assert some control over who comes in and out of their home? What mechanisms do they see as being able to be put in place to do that? Would they support people having full and complete control within [PCS] models that would essentially be more of an agency with choice model where you would have some control over just who comes in and out of your home, and how would they see that working? Recognizing that we have limited amounts of funds available and, every time you increase wages and benefits to attendants, there's going to have to be a give somewhere in the system. And that give is generally in the number of hours of service individuals with disability actually receive. So, given cost neutrality, when you're advocating for increased wages and benefits for the workers, where does that money come from?”

In summary, consumer-direction in PCS in NY, as demonstrated most visibly by the expansion of the CDPAP model, has received less support and attention than the traditional, agency-based PCS program model by state and city officials, many providers, and even less by the unions. This despite it being the fastest growing program in the state. Consumer advocacy organizations are working to make the program more available and bring it “above the radar” so that consumers who wish to choose the optional program

will be able to do so. State and city officials deflect accusations of any organized constriction of the CDPAP as demonstrated by one official from NYC,

“The numbers of people they’re talking about is small... small compared to what’s here in NYC. There’s Buffalo.... I think they have 200 CDPAP cases... and a few in Rochester. I mean, that’s why NYC is always the bad guy, you know. All these allegations about the program... People think that they... that we are just the same as everybody else in the state, but we aren’t, you know. I mean, look, we’ve got 60,000 clients in the PCS program. Wouldn’t...wouldn’t you think there would be a loud outcry if they were suffering in these kinds of ways? They’re receiving all their hours. I mean, we certainly have very lively consumer advocates here in NYC and we’re not hearing this. Why are they so vocal about this upstate? It’s costly to set up a consumer-directed program. I can understand why some counties aren’t doing it. Overseeing all of this, and the work you have to do to prepare for it. I mean, you have to...you really have to have people dedicated to determining if that...if it’s appropriate and so on. And maybe that’s why...I wouldn’t be surprised that that’s why the counties won’t do it, because you have to have a whole unit for four people.”

When state and city officials do speak of their concerns about the expansion of the CDPAP, they voice the issue of potential fraud and the need for there to be better quality oversight of the program before it grows any larger as explained below. Their focus on potential fraud, however, is not limited to the CDPAP and includes both models of the PCS program. Important to note, Governor-elect Elliot Spitzer’s Transition Team had just, days before, visited the DOH and the issue of Medicaid fraud was reviewed extensively prior to state and city officials participating in this study.

Quality Assurance and Consumer Fraud Concerns

The NYS DOH has a large staff devoted to monitoring quality in Medicaid programs. In regards to the PCS program, there are both State and Local Social Services District quality assurance mechanisms. The local social services district, which authorizes the Medicaid funded PCS program, has an obligation to monitor the provision of authorized Medicaid services. Methods may vary across districts but may include things

such as review of nursing supervision reports, maintenance of client complaint hotlines and grievance reports, consumer satisfaction surveys, and more.

The State Department of Health also helps assure quality of all home care services. The OMM monitors Local District Social Services for compliance with State PCS program regulations. The Department of Health's Office of Health Systems Management (OHSM) monitors the home care agencies providing home care services, irrespective of payer source. This is accomplished through the office's home care licensure and surveillance process. The OHSM also sets the health standards for professional and paraprofessional home care agency employees (e.g. criminal background check requirements, aide training requirements, frequency of nursing supervision visits, and documentation of service requirements).

Quality oversight begins in the approval process when the competence and character of the proposed operator is investigated. According to one state official, character and competence are reviewed, not financial feasibility or any public need. A potential licensed agency operator submits "resume-type information" to the central office for a review that includes a criminal background check. (For Certified Home Health Agencies (CHHAs) there's a certificate of need process and a cap on the number allowed operating in any one region of the state). Officials report that opening a licensed facility can take approximately six months to a year, depending on how organized the applicant is. Final approval is made through the public health council, where scheduling a review on the agenda can take up to two months. After approval from the public health council, the applicant moves into the pre-opening survey track where they are required to submit comprehensive policies and procedures for the field staff to review. These consist

of a manual containing for example, job descriptions for all types of employees and policies and procedures that will demonstrate that they'll be able to operate the home care agency in compliance with the regulations. The regional offices offer a lot of guidance in the application process.

Surveys are another means of quality oversight utilized by OHSM with the counties. Inspections of each agency contracted with the state are conducted (in theory) every three years, though the staff acknowledge that this goal is not being met for all of the approximately 950 current licensed agencies in the state. Because there is a significant turnover or, as one interviewee stated, "they're opening and closing as we speak", it is difficult to meet the objective of inspecting each licensed agency every three years.

When a survey is conducted on a licensed agency, the rule of thumb for the quality oversight division is, according to one state official, to send one person for two days or two quality oversight staff for a one-day survey. And, if a complaint has been lodged against an agency providing PCS and the state has not surveyed the agency in a while, the staff report that they will be as efficient as possible and do a complete survey, including an investigation of the complaint. The unannounced survey visits often find agencies not currently in business. One state official explained that there are about 950 licensed agencies but some of them that are non-operational. The OHSM seeks to get the license back if they're not operational. Some of them are big companies that are chains that have multiple sites. Some, referred to as "mom and pops", are operating out of their homes.

There are four regional quality oversight offices throughout the state that report back to the main bureau office in Albany. Each regional office has a program manager for homecare. Every four to six weeks there is a meeting in Albany of all program managers and the state staff. Daily phone calls and electronic mail provide an essential communication tool in between the in-person meetings.

The OHSM does follow up with provider agencies to verify that each participant has the correct doctor's orders on file to receive services as per their contract with the state. Each provider is required per regulation to do some quality assurance activities themselves, a yearly survey of their participants regarding quality of services rendered, for instance.

Providers are required to manage their own quality oversight by reviewing all discharges before discontinuation of services. In addition, quarterly quality improvement meetings are required. Regulations require that representation of all the services on their license are at the meeting, including, as of 1995, a consumer (Operational Regulations, Title 10, 765 & 766. LTC patient's rights, planned care, establishment in 760-762. Definitions of all types of health care facilities in 700.2).

At the state level, one goal of OHSM is to inspect provider agencies every three years but that is not always possible. There are approximately 950 licensed agencies in NYS and as one state official noted, "they are opening and closing as we speak". State officials confirmed that monitoring the quality by provider agencies is an ongoing goal.

At the local level, a major quality issue, according to one city official, is monitoring the workforce in regards to client coverage. Very often, according to city officials, when clients first come into the system they will go through 20-30 attendants

before they feel comfortable with somebody as their caregiver. But once they do feel comfortable, that person will keep on working with them. Quite often, the attendant doesn't necessarily want to work with that one person exclusively or for years on end, so it's better for the provider agency to have several people who the client is comfortable with. HRA discovered that there were quite a lot of instances where there was one home attendant who was working seven days a week with a single client. This, according to city officials, is bad for the worker and bad for the client. The client has to have more than one worker so they are not totally dependent on one worker. Having at least two people rotate through is important. And yet one of the things that government, according to one HRA official, has to be careful about is not dictating to the providers how they handle this issue. According to one city official, HRA is obliged by CMS to withdraw and leave this in the hands of the provider, assuring an arms-length relationship between the provider and HRA oversight.

In other efforts to affect increased quality of LTC services in NYS, effective July 2005, the Division of Consumer and Local District Relations Bureau of LTC reassigned State staff responsible for several Title XIX HCBS and programs. The realignment of staff was intended to all the OMM to maintain current Title XIX HCBS; develop and implement the Nursing Home Transition and Diversion Waiver; and, continue to work on the LTC restructuring efforts described in Governor Pataki's January 13, 2004 Interim LTC Restructuring Report (2007).

Federally Mandated Home Health Hotline

A statewide federally mandated home health hotline, directly linked to the OHSM Quality Oversight Bureau in Albany, report approximately 1500 calls per year (interview

with OHSM staff), with approximately half to two-thirds from the NY City metropolitan area (two-thirds of the providers in NY are in the NYC area). According to OHSM the number of complaint calls has averaged at around 1500 per year for over a decade.

OHSM staff report that there have been “bumps” in the number of complaint calls during key periods of stresses in the system, such as a union strike, though this was in NYC and not in the pockets of upstate that do not have an organized labor market.

The process for addressing hotline calls was explained by OHSM staff. A hotline call comes in, for example, when a worker calls in sick and the call is sent back to the field office that houses the provider responsible for the person calling in. The staff in Albany may take the call but they’ll explain that it is better for the local field office to address the complaint. OHSM staff report that consumers from “downstate” are very aggressive in wanting the state office to take care of the call and they report that there are definite regional differences. OHSM staff hotline staff describes these by explaining the regional personal care worker shortages and difficulty upstate workers have in comparison to those in the NYC region. Within the NY State Office of Health Systems Management (OHSM), the Bureau of Long Term Care Reimbursement oversees PCS programs.

The Home Care Services Program Quality Control Unit field staff conducts random, unannounced quality control visits to assess the quality of service delivery and client satisfaction with the vendor agency. In addition, a Complaint Tracking Unit receives, evaluates, investigates and ensures resolution of complaints received in response to home care service delivery. The unit maintains a telephone hotline where service complaints are registered and investigated to ensure that any potential risk to the

client is removed and corrective actions are taken as needed. Consumers are given the hotline number at the initiation of service and vendors are required to provide consumers with the hotline number at least once annually. Quality control field staff also provides the hotline number during unannounced quality control visits. Consumers can also access the number through 311 or on the HRA website. All complaints are taken seriously and handled as expeditiously as possible based on their severity. HRA requires the vendor agency to have a registered nurse visit a client and resolve the risk condition within 24-hours for a complaint that is categorized as high-risk.

Quality Oversight by HRA in NYC

HRA requires that providers demonstrate quality. There is a mechanism built into providers' contract with HRA that requires them to demonstrate quality. In addition HRA visits each provider, at least, every 90 days. There are two different quality reviews. The CASAs are responsible for what's going on with client in the home. It is their responsibility to follow-up on the patients they've referred to various provider agencies and what's going on. They are also required to visit the client in the home, at least, every 90 days. Within the CASA, there are two arms of service, the social worker arm, and the nurse arm. Case managers are responsible for the day-to-day oversight and the nurses are responsible for putting the services in place and for the clinical evaluation of those services. Hours of need are determined by a team evaluation after both the social worker and the nurse prepare their evaluative report. Sometimes they go to the client's home together, and sometimes separately.

Automated Telephone System (ATL)

One improvement assisting with quality oversight of the PCS program, according to both program officials and directors of provider agencies, is the Automated Telephone System (ATL) now in place for all traditional PCS program providers in NYC. Directors of provider agencies expressed confidence in this system as a major deterrent to potential fraud by workers. The system involves all PCS workers assigned by provider agencies calling into an 800# when they arrive to a client's home and again when they are leaving the home at the end of their assigned shift. In addition to verifying the hours worked, PCS workers indicate by punching in set codes the actual tasks performed during the shift. Some fraud with the system has been identified. A worker who has become close to a client and their family and who may be running late to work could, for example, request the client to call the 800# for them, indicating they've arrived to work when they had not. However, according to one director, because the worker's Social Security # is their ID, it is not believed to be a common practice.

The ATL system is now in place with all the traditional PCS program providers and with the CDPAP provided through the newest agency contracted for the optional service, though not, as yet, adopted by the original agency that was the sole provider of the CDPAP. Additional goals for quality improvements for the PCS program as stated by directors of provider agencies include increasing the quality of candidates looking to be home attendants and creating a larger pool of workers who speak a variety of languages that are in demand by clients served. One director stated emphatically that their biggest barrier to improved service was finding good, qualified field employees with appropriate language skills.

State and city officials were most vocal in admitting that, until recently, the state had not paid close attention to potential fraud in the delivery of PCS and, with the increase in the CDPAP, it needed to. State officials responsible for quality oversight of the PCS program gave examples of encountering resistance in their survey process regulated by the state. They report that on several occasions they had to request assistance from the state officials overseeing the PCS program to intervene and require county agencies to provide, for example, proof of original doctors orders, to complete their survey process. State officials report that some discrepancies in oversight were affected by the changing of the regulations, even before Olmstead. One major difference noted between the newer vs. older operational regulations in oversight is the newer requirement of the need for a consumer to be on the quality improvement committee. As of 1995, there had to be representation of all services on their license at quality improvement committee meetings, including a consumer (NYS Laws and Regulations 764, Title 10). State officials concede that they are unable to conduct mandated surveys every three years on every agency that contracts with the state, though that is their target. Regional offices and daily communication with staff throughout the state are the steps they have taken to reach their quality oversight goals.

Daily communication is also the manner in which state and city officials learn about individual cases of fraud that influence their views on the CDPAP. For example, one official reported on a recent case where attempts were made by an agency to reach a consumer per the agency's quality oversight practices.

“After no response over a period of time, notice was sent to the state to inform us that the client was not responding. Perhaps they had been admitted to the hospital. We receive a report from the Department of Investigations for Medicaid Fraud alerting us to clients that have been

hospitalized who are *double dipping*, where Medicaid is being paid while the client is hospitalized. By the time this information is available and given to the agencies months, often years, have gone by. Consumers continue to sign the time sheets for their caregivers to submit, hoping that they will be discharged soon, and not wanting to lose their caregivers.”

Directors of provider agencies from the traditional PCS program have more oversight on monitoring whether fraud is occurring and report that they have mechanisms in place to double check on whether the worker they employ is providing care to the client or not. As one director stated,

“Most of the people need the care they’re getting and want somebody there. The cases where the family has taken advantage of that situation by fraudulent means are rare”.

The problem for fiduciary agencies providing the CDPAP is that they are caught in between. State and city officials want agencies supporting the CDPAP to have more oversight but, because the consumer is the home attendant’s employer and not the agency, there is a problem. Consumers complain of agencies being too intrusive in their lives and with the supervision of their workers, while state and city officials are requesting agencies monitor payroll and other services to counter any fraud that appears to be occurring. It is apparent that a few key examples of fraudulent behavior reported and dealt with within the CDPAP program have influenced the views of state and city officials.

Union officials expressed positive feedback on HRAs recognition and prevention of fraudulent activity in the PCS program and stated emphatically that fraudulent activity was limited to a few cases. As one official reported,

“The union is, yeah. I mean, well, the union has sort of taken this neutral position on it. You know, sort of acknowledging that we need to...to reorganize and make New York State’s healthcare system more

efficient, but I mean, the bottom line is he's telling us he wants to cut two billion dollars out of Medicaid for the state and I don't know where in the world he's going to get it without hurting healthcare and hurting workers and hurting everybody else. There may be fraud here and there, but on the homecare side, there's fraud...there's some amount of fraud that, you know, doctors are getting kick-backs from false patients and, you know, we know that's true in the Russian community because the addresses of homecare workers are often fake...we know that's going on. And there's some mafia stuff in that. You know, it's *tiny* compared to the budget, I mean, and the amount of stuff you *don't* hear about is indicative of how clean it is. I mean, there's a ton...most of these places are community based, you know, probably inefficient, you know, not-for-profits that are based, you know, in and around community groups that are maybe a little bit too politically tied, some of them. So, there is probably some inefficiency in the administration or there has been in the past. But at this point, there's no money, unless you're providing care. And there's nothing to skim. You know, it's just...there's just no meat on the bone here for fraud, unless you are literally doing fraud where you're lying and not providing care, and you can't get away with that. Clients want the care they need. There's just not money in the home care. HRA is really, at least that side of HRA is really... really good at knowing what's going on. I mean, that the good part. The bad is that they've infantilized most of the directors who can't do anything without HRA telling them what to do."

In summary, state and city officials are the one group most concerned about actual past and present fraudulent activity in the PCS program and appear quite wary and justified in their actions to limit the growth of the CDPAP because of this belief. Responses to questions regarding the PCS budget, however, raised concerns for each of the other groups.

PCS Budget

Responses to questions concerning the PCS budget covered a broad spectrum of concern to three of the four participant groups. As noted in Table 21, state and city officials did not express budget concerns though providers, the unions, and consumer advocates did. Important to note is that, at the time of the interviews, Governor-elect, Elliot Spitzer, had sent a transition team ahead of his taking official office in January of

2007. The state and city officials interviewed for this study had all met with the Spitzer transition team days before and reported to this investigator how they had justified the PCS budget, accounting for each aspect of the program.

The Bureau of Long-Term Care Reimbursement sets the rate county by county and with HRA. Office of Medicaid Management oversees the Department of Health officials that facilitate the PCS program. The issue of budgets is not their concern, the running of the program is. Directors of Provider agencies, however, have a very direct connection to the funding they receive and had a number of concerns, as did the unions and consumer advocates as explained below.

Provider Agency Concerns

Agency providers expressed concerns about the budget and how they balance the allocation of scarce resources within their agencies. They expressed concerns about recruitment of educated workers, high turnover in workers, and the caliber of the current home attendant workforce as it differentiates from an earlier workforce of mainly immigrant women content to have work in their community. As one director stated,

“Ten years ago, you got more of an individual that was really interested in the healthcare/homecare business. And you’d say to them, “What interests you, what got you here?” They’d say, “Oh, I took care of my mother, or I took care of my aunt.” That’s what...there was a true interest. Now if you ask them, they’ll say to you, “I need a job.” And the problem with that is, once they finally get into it, they go through the training, they’ll pass the training. They’ll get into it and they’ll say, after a few months, “You know what? This isn’t really what I want to do. I’m coming into an individual’s home. I really don’t know what to expect. I have to assist somebody from the bed to the bathroom. I have to help them bathe, I have to help them shave”. All those things they learn in training, but then when they actually get into it and they’re doing it every day, they say, “Oh, boy, I think I’ll go work at McDonald’s and have a different scene.”

In addition, directors of provider agencies expressed upset over the administration cap and the inability to save funds by thinking innovatively and providing preventive care. According to state officials, counties have a maximum 28 percent administrative cap to adhere to when budgeting for the year. Provider agencies in NYC, however, are accountable to HRA, which sets a much lower cap for administrative costs for agencies within the five boroughs. As one director reported,

“I’ve got a million and half dollars to run the PCS program and what it comes down to in reality, what I have left to pay administrative, reflects seven to eight percent. That’s seven to eight percent for everything... the office space, the phone... the citywide average is over that, maybe eight percent. So it’s like 92 cents, you know, goes to direct care out of every dollar. Yeah, about 92 percent goes, yeah [thinking]...you know, it’s home attendant wages and benefits, ... so we’re nowhere near the 28 percent [laughing] cap in upstate. We’d love a ten percent cap! I could do wonders with a ten percent cap. But, like I said, I think the government, because this is such an extensive program, you know, that’s...the challenge. For example, I really believe that with, you know, social workers, adding a medical social worker into the mix over here would enhance patient care and we could take it to... I really believe we could take it to a certain outcome that would, you know, show an overall savings. And so we’d spend \$60,000 for a social worker... that gives them benefits and what not, you know. We can pay. And with one visit a month, they’d probably be paying for themselves. Right now we deal with emergencies that could be prevented if we had the medical social work staff available. Hard to...hard to spit that out if you can’t show the numbers up front as to where it would go to reduce overall costs.”

Union officials expressed concern with the budget as well, though focused more on the workers and their wages and benefits.

Union Concerns

In regards to the budget, the unions are most concerned with advocating for the rights, wages, and benefits of their members. Consumer *direction* is not an issue at the top of their agenda as, at this stage, the CDPAP participants make up only a small percentage of the PCS program and the independent providers they employ are not easily

organized. As such, the unions focus on continuing their mission of growing the division of homecare workers in NY and work to increase the number of agencies to become members.

Wages have gone up considerably for unionized home care workers in New York City. Because of the *Living Wage Bill*, the starting wage for home attendants is now \$9.60/ hour. After their probationary period they move to \$9.90 on the 1199 contracts. The minimum wage for NYS as of January 2007 is \$7.15/hour, up from \$6.75 in 2006, which is up from \$6.15 in 2005, while the federal minimum wage, effective July 24, 2007, was raised to \$5.85/ hour. In addition to the living wage legislation passed in 2002, SEIU 1199 put together a state plan amendment to provide health coverage for home care workers. Prior to that, many of the workers who were getting paid \$7.00/hour were eligible for Medicaid. According to union officials, the program put together by SEIU 1199 had NYC permit 1199 to certify workers who were eligible for Medicaid so that if they didn't work enough hours as homecare workers their Medicaid coverage would not be interrupted. In 2001, \$160 million was allocated to SEIU 1199 for the demonstration project and union officials report that each year since, this National Benefit Fund has received anywhere from \$138 - \$160 million. SEIU 1199 officials appear to be very proud of the contracts they've negotiated for members. As one stated,

"We fully...*fully* understand, and we understand our workers. We understand that the system is a means of providing healthcare. These workers provide healthcare. They're caregivers, and they...most of them are and, at the end of the day, that's our primary concern. And quality care includes continuity in care and a stable workforce. And that means a well paid and a well provided for workforce that can stay in a job, and whose family gets health benefits and they can stay there, and then they make a living and maybe they even get a pension. And they stick with it, and they stick with their pensions. And, you know, it's...this is something I hope that you get a chance to look at. Because no one has quantified it as well

as it should have been quantified. The stability of the workforce since 2000, on the personal care side, and the...the savings and no new training costs, and the quality of care to the patients who are keeping the same aides for five or six years as opposed to six months – this is a direct result of what the union has accomplished. And the...the not-for-profit owners are very happy about that. And we can take credit for the outcome. No question we take credit for this outcome. Absolutely we take credit for it. And we deserve credit for it. And we intend to do the same thing on the home health aide side, which is abysmal. You know, the workforce retention situation is horrible on the home health aide side. I mean, it's a revolving door, a revolving door. There are people who don't care if they're unskilled or not, and caregivers that aren't sticking with the job. The ones who do stay are the ones who want to do it and are inclined to do this work. And the union has made it possible for them to stay doing this work. They're not making a lot of money, but they're making enough to live life. And that's good for everybody. Yes, we do take credit. And, you know, you talk to any of the agency owners, they will share the credit with us, and they're very proud of the improvements that they have on the personal care side."

While consumer advocacy organizations expressed positive opinions on what the unions had accomplished, they did not advocate as strongly for increased wages and benefits for home attendants, who are already represented by unions, stating that the disparity between the wages and benefits for home attendants over those of home health aides has contributed to loss of morale in the workforce in NYS as a whole.

Consumer Advocacy Organization Concerns

Consumer advocates expressed concern regarding the PCS budget as it affected, primarily, the expansion of consumer direction within the PCS program. Namely, they feel there is a concerted effort to keep the CDPAP model in check by state and city officials and feel a commitment to demonstrate that, in the long run, allowing consumers the option of hiring independent providers allows them to receive the hours of PCS they are due. At the same time, there is an assertion that those consumers who do receive all the PCS they require end up costing less. Less because they are independent and

remaining in the community and not ending up in the hospital or nursing home due to an agency not being able to provide the care they need for whatever reason, be it transportation, language, or inability to provide the hours when the consumer needs them. Although the CDPAP may have begun as an initiative of the younger, disabled consumer, the elderly who have opted to participate in this program are benefiting greatly from the opportunity to self-hire and receive their total hours of care.

In summary, provider agencies, unions and consumer advocacy organizations all expressed concerns related to the PCS budget and how to provide PCS in a fiscally sound way while accounting for the needs of those they represent. Consumer advocacy organizations are working closely with provider agencies and collaborating with the unions to work on issues such as how the necessary workforce for consumers will be recruited, how it will be trained and who will do it. Each of the three groups expressed a concern about how to make caregiving a respected occupation and a calling for those who choose this career route. While provider agencies have experimented with a variety of interventions to improve the recruitment and retention of direct care workers through the use of, for example, transportation, child care, career ladders and referral bonuses, it is the PCS budget that ultimately influences the agencies' capacity to create worker incentives to maintain workers for those in need of PCS.

In conclusion, competing logics expressed by representatives of key stakeholder groups indicate their views that a number of individual barriers concerning rights centered on Olmstead that pertain to consumer direction, access, quality oversight and fraud prevention, in addition to budget concerns, are hampering the expansion of the PCS program, especially utilizing the optional consumer-directed model utilizing non-

unionized, independent workers. Chapter 5 addresses the significance of these beliefs, the limitations of this study and recommendations for further research.

CHAPTER 5 – DISCUSSION

Meaning of Findings in Relation to Research Themes

This institutional case study was designed to examine and describe the environment in which the organization, the NYS PCS program, exists. Using an institutional perspective, the study focuses specifically on the PCS program's governance systems, key stakeholders and their belief systems, or logics. By examining the institutional environment where the program is situated, together with trends in the program over a five-year period and interviews from key stakeholders, it is possible to see competing beliefs in the delivery of PCS in NY and better understand how these competing logics affect change and inertia in the PCS program. Each of the barriers summarized below from the findings are not huge, yet combine to create a bottleneck for expansion of the program.

Aim 1

Aim 1 describes the NYS PCS program in terms of its governance, organization, and management structure. The decentralization of the PCS program is evident in the varied access, integration, and application of PCS across 57 counties and NYC. Documentary research and interviews with state and local officials confirmed that the NYS PCS program is not well integrated with other LTC programs in the state. In addition, there are wide variations in access, support, and level of service for the Consumer Directed Personal Assistance Program (CDPAP) across counties and the five boroughs within NYC, despite broad support for the program. Various assessment tools

are used in NYS to assess the needs of participants in the various programs offering HCBS in NYS.

Rate setting and administrative caps differ between upstate and NYC, a source of concern to provider agencies in NYC, where approximately 80 percent of the PCS program is provided, struggling to accommodate a cap that requires 92 cents of every dollar be directed to service provision. The demographic shift of growth in the aging population of NYC has resulted in a higher volume of consumers receiving care, and increase in the number of hours of care and an increase in the cost per hour of care. The expansion of the PCS program in NYC alone has increased from approximately 46,000 in 2004 to 63,000 in 2006. Costs for the PCS program have also grown from approximately \$1.4 billion in 2002 to \$2 billion, currently (Interview with NYC officials, 2007).

Since 1982, the NYS Medicaid Personal Care Services (PCS) program has offered a state plan optional benefit for PCS and several ways of addressing the growth of the PCS program have been considered over the years. Limiting or reducing the number of consumers eligible for the PCS program has not been an option since Medicaid is an entitlement program. Neither NYS nor NYC has the ability to limit the number of recipients who are eligible.

In 1996, the legislature passed Social Services Law 365-f establishing the CDPAP to support chronically ill and/or physically disabled individuals receiving home care under the Medical Assistance program greater flexibility and freedom of choice in obtaining such services.

One approach to both improve the management of PCS and eliminate the fragmented LTC services received by recipients in need of these services is to expand and

move clients from the PCS program to Managed LTC Plans. There is an assertion that clients would be better served. Enrollment in Managed LTC is voluntary and, at any time, if the client is dissatisfied, they can return to the PCS program.

Workforce issues are also affecting consumer access to PCS. According to NYS officials, creative actions taken by providers to ease challenges that confront the PCS workforce in NY have been required to meet the need for caregivers. Even with the highest estimated numbers of workers, there are pockets of shortages for workers in the traditional, agency-based models of PCS, and independent providers hired by consumers who are eligible and enrolled in the CDPAP.

The NYSDOH are in the midst of gearing up to address a large turnover in long-standing state and city officials due to aging baby boomers. There are efforts underway to transfer knowledge to newer employees who will soon be responsible for the administration of the PCS program. Many of the state officials currently responsible for the PCS program in NY have been involved from the beginning.

Aim 2

Aim 2 examines trends in the NYS PCS program, specifically in the participants and expenditures, from 1999-2005. Participants in the NYS Medicaid PCS program, overall, declined steadily each year from 1999 through 2005. According to directors of provider agencies and consumer advocates, this is attributed to an effort by NYS to divert potential PCS program participants into Medicaid managed care programs, usually those participants that are assessed for less acute needs, leaving those with higher acuity needs in the PCS program. There was an overall total decrease of 5 percent from years 1999-2005.

Although the traditional PCS program declined over time, there has been a steady increase in the number of eligible clients opting to participate in the CDPAP, from 5,717 in 2003 to 7,505 in 2005. The CDPAP increased by 17 percent from 2003 to 2004 and 12 percent from 2004 to 2005, for a total 31 percent increase from years 2003-2005. The trend of increased use of the CDPAP is attributed, according to state and city officials and provider directors, as an increase in the number of elderly using what was long considered the option most utilized by younger, disabled participants. In addition, provider agencies are recommending “difficult to serve” clients, both elderly and younger disabled who fit the criteria for that category, to consider the CDPAP as an option for receiving necessary PCS.

Participant numbers confirm a relative decrease in participants in the PCS program in NYC, following the trend for the state overall, at a time when there is a steady increase in participants enrolled in the Lombardi Waiver Program, and in the Medicaid Managed Care Programs, an alternative available option for PCS. In 2005, the last year of the study, NYC had 2,100 participants enrolled in the CDPAP, 28 percent of the total 7,505 CDPAP participants for that year of the program. The remaining 72 percent of participants are spread out over the other 58 counties, confirming the increased use of the CDPAP option for those participants in rural areas not easily served by traditional provider agencies.

Expenditures for the NYS Medicaid PCS program, however, continue to rise demonstrating that, although participants are declining in number, the program expenditures continued to increase from \$1.46 billion in 1999 to \$2 billion in 2005. NY spends more than double on PCS per participant compared to the national average.

Adjusting for inflation, overall expenditures for the PCS program increased by 139 percent from 1999-2005.

As the number of participants remains stable or decreases, expenditures for the PCS program continue to increase, one justification for the referral of potential enrollees to less costly Medicaid Managed programs as a cost containment measure in NY. From 1999-2002, NYS ranked 3rd in per participant expenditures compared to the US average, rising to the rank of 1st for 2004 and 2005. In NYC, home health aides increased by nearly 30 percent over the five-year study period. The design of the NYS agency-based PCS program primarily stems from the early unionization of PCS workers and the traditional support for unions in NYC that has resulted in generous worker wages and benefits, and a stable program.

Aim 3

Aim 3 examines how competing logics of key stakeholders are influencing change and inertia in the NYS PCS program. While the findings on this case study of the NYS PCS program document a well-established program with agreement on many aspects of its operations, competing views from the four participating groups studied were made evident from interviews, primarily in five areas, and held by representatives of each of the four participant groups. The five primary areas of concern voiced by study participants included: Olmstead Planning; Access to Services; Consumer Direction; Consumer Fraud; and the PCS Budget. While consumer fraud concerns dominated the expressed beliefs from state and city officials as reason for barriers to the expanding consumer-directed model (CDPAP) vs. the traditional, agency-based model, directors of agencies were most concerned about how to manage diminishing budgets to provide PCS,

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manage workers, and remain competitive as provider agencies. Union officials expressed a strong desire to see an increase in wages and benefits for those the workers they represented and were mainly focused on this issue, although currently, only on agency-based workers in NYC and throughout NY, and not independent providers. Consumer advocates expressed strong beliefs regarding four of the five key areas of concern and were the most outspoken advocates for both consumers and workers.

The pressures from key stakeholders, both individuals and collective disability groups, to expand consumer-directed delivery of PCS in NY have challenged the status quo of the NYS PCS's, primarily, agency-based program, leading to structural and management changes and the expansion of the optional consumer-directed alternative delivery model, though not without push-back from some state and city officials.

Significance

Home care is one of the fastest growing industries in NYS, driven by government policy and paid for by tax dollars (Confessore & Kershaw, 2007). Currently, the NY State Attorney General, Andrew M. Cuomo, is in the middle of a two-year investigation into fraud in the home health industry, including scores of cases where agencies billed Medicaid for work that was never done (Confessore & Kershaw, 2007). A New York Times article reports that, until recently, state officials had not paid close attention to home health care fraud. NY only recently became the second state, after Texas, to create a Medicaid inspector-general's office, and Governor Elliot Spitzer, who initiated a number of current fraud investigations when he was attorney general, has made reigning in Medicaid fraud a key priority (Confessore & Kershaw, 2007).

There appears to be strong evidence that the level of service and care provided by the NYS PCS program and its sustainability has depended on a broad coalition of stakeholder groups and public support for the program. And yet, while there is an expressed goal for shifting services from institution to home and community-based care, as desired by consumers and those that advocate for them, there was also a skeptical stance expressed regarding the CDPAP and expansion of this option within the PCS program. Officials and provider agency directors cited a need for quality oversight of the PCS program as a concern before there is an expansion of the CDPAP. The prevailing logic, as expressed by state and city officials and directors of traditional agency providers, is that, until there is more quality oversight of the CDPAP, the traditional, agency-based model of PCS, offers a better job of providing care to those in need of PCS with more oversight in the quality of care given. The consumer-directed option for PCS, the CDPAP, is “under the radar” of available options offered to consumers according to consumer advocates who expressed their views that, if consumers were informed more fully about the CDPAP, more would choose this option over the traditional, agency-based model that presently dominates the program.

Currently, those most likely to be referred to the CDPAP fall into the description of those deemed “difficult to serve”. In upstate NY, this might be because of lack of available agency-based staff to provide the hours of care someone in a rural setting might need. Difficulty with transportation or limited hours of care might lead an agency to refer a client to the CDPAP if assigning staff to the case is too difficult. This appeared to be the case more often in areas outside of NYC, as opposed to a client resisting care or having mental health issues or behavior problems, a more prevalent problem in NYC that

would place them in the *difficult to serve* category. Program officials and provider agency directors consistently expressed this attitude that stands out as a clear barrier to expansion of consumer direction in the PCS program.

The state and city officials responsible for leading and managing the NYS Medicaid PCS program appear to be smart and capable people committed to providing high quality care in an integrated way to the most vulnerable populations in NY. The same can be said for the directors of provider agencies, union officials, and consumer advocacy organization representatives interviewed for this study. The various components of the program are of high quality. However, less effort is spent on integrating the high quality components throughout the system/state to counter concerns of consumer fraud that prevent the expansion of available consumer options. NYS has the opportunity, if it focuses on developing a truly integrated approach to PCS, to be one of the most comprehensive and effective LTC provider systems in the country. Limitations

As states work toward rebalancing their LTC systems, assessing their progress allows feedback to all stakeholders interesting in the outcome of those efforts. Steve Eiken, principal investigator of a model profile for assessing a state's LTC system (Eiken, Nadash, & Burwell, 2006) recommends that, given the expertise and time, any state may complete a similar state profile. This study does encompass certain parts of a comprehensive profile format suggested as a technical assistance guide states might use to assess their own LTC system as suggested by Eiken et al. (2006), ones that required less time to complete than others. Basic information, such as a list of available programs, their administrative agencies, and the services they commonly provide, were relatively easy, though time-consuming, to find. Compiling and analyzing the demographic and

utilization data was relatively easy, given the PAS Center collection of such data. Other aspects of the study, such as interviewing and analyzing competing logics in attempts to explain change in one State Medicaid program, took more time. The actual time required for each component varied, based on the availability of information on the LTC system in NYS and the limited expertise of the doctoral student developing the study.

The institutional history and memory shared by long-serving public servants (state and city officials, directors of agencies, union officials, and consumer advocates) who participated reflects much of the historical and political factors that influence systems change and assisted in the investigators understanding of both change and inertia in the NYS Medicaid PCS program. NYS would be well served in undergoing a state profile (Eiken, 2006) conducted by a reputable and experienced research team to assess its rebalancing efforts. Such a funded endeavor would benefit by including a consumer focus in its assessment process, something lacking and a clear limitation in this study. In addition to not including the consumers' perspective when assessing and analyzing competing logics, the small number of study participants interviewed (22) is also a limitation of the study. Alternate explanations may account for inertia of consumer direction in the NYS PCS program. Future research would do well to include consumers and a larger sample to assess what influences are shaping the program.

Four principles underlie quality analysis of qualitative data (Yin, 2003): 1) all the evidence is attended to; 2) all rival interpretations are addressed; 3) the analysis identifies and addresses the most significant aspect of the case study; and, 4) the investigator uses his or her own prior expert knowledge. These principles governed the course of the study, including data collection from each study participant group, the data analysis, and the

reporting. All efforts were made to match the methods appropriately to the aims and issues outlined above in order to produce a high-quality document that will be useful to researchers and policy-makers interested in LTC policy and programs.

Future Research

Future research on PCS programs would benefit from an examination of competing beliefs of different key groups including consumers and the workforce serving them, in addition to the policy makers and those responsible for program outcomes. A study polling the opinion of 20 leading researchers with an interest in the direct-care workforce (Salter & Wilner, 2006) yielded a broad set of ideas asserting a future research agenda that includes: an in-depth national and regional description of the size, diversity and geographic variation of the workforce; investigation that goes beyond single intervention studies to examine the inter-relationship and relative impact of pay, benefits, training, leadership, and socio-demographic variables on job satisfaction and retention; more research that links specific workforce initiatives to quality outcomes; and, a focus on the effect of “re-balanced” delivery systems, such as consumer-direction and assisted living models, on the workforce. Additionally, in regards to future research, the UCSF PCS Center (2007) has compiled a five-year plan for future research that is inclusive of all aspects covered within this institutional case study and would offer a natural trajectory for expanding the research begun here. Participants from this case study suggested it would benefit the investigator to return to NY in three years to document another data point in NY’s pursuit to provide PCS, a welcome invitation to any investigator and one that was highly appreciated by this novice doctoral researcher.

The results of this study will stand independently as an analysis of the institutional environment and evaluation of one important state's program, but they may also help build a foundation for other case studies on state Medicaid PCS programs. In NY, unless there are countervailing forces to the status quo, efforts toward increased consumer direction in the PCS program will be thwarted. The results of this case study may create a better understanding of the conditions necessary for PCS program development in other states, and because it is on the large and established NYS PCS program, may make a contribution toward health services research and policy.

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Appendix A: A Generic Conceptual Framework for Organizational Field Analysis

Appendix B: Letter of Introduction to Study Participants

Date

Dear -----:

I am writing to ask for your participation in a study on the New York State Medicaid Personal Care Services (PCS) Program. This study is being conducted as part of my doctoral dissertation project at the University of California, San Francisco (UCSF) School of Nursing, and aims to contribute information to a larger study by Dr. Charlene Harrington RN, PhD, Director, UCSF Center for Personal Assistance Services <<http://www.pascenter.org/home/index.php>>.

The purpose of the study is to examine and describe developments of the New York Personal Care Services Program, focusing specifically on three key areas: its governance (structure and management); trends in the program over time (1999-2005); and, current logics (beliefs) regarding the program as related from key stakeholders involved in the development of the program. Your participation will involve a telephone or face-to-face interview (approximately one hour and, with your permission, digitally recorded) about the PCS program in New York.

Your participation in this study is entirely voluntary. Although there are no direct benefits to your participation, by providing this information you will be making an important contribution in identifying the current development of the Medicaid PCS program in New York. If you choose to participate the information that you submit will be handled as confidentially as possible. Participants may decline to answer any question or to discuss a topic and may terminate the interview at any time. All statements will be attributed anonymously. The study results may be published in a dissertation. Summary findings may be made available to the public and policy makers. Data on individual clients are not being requested.

If you have any questions now or at any time about this study, you may contact me or the Principal Investigator, Dr. Charlene Harrington, who may be reached at UCSF telephone number 415-476-4030, or by email at Charlene.Harrington@ucsf.edu; or the UCSF Committee on Human Research, which is concerned with the protection of volunteers in research projects. The Committee's office hours are between 8:00am and 5:00pm Monday through Friday. The telephone number is 415-476-1814 and their mailing address is: Committee on Human Research, Box 0962, University of California, San Francisco, CA 94118.

Thank You,
Toby Adelman RN, MSN
UCSF School of Nursing
(415) 902-3298
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APPENDIX C: Study Questionnaire for New York State and City Officials

SECTION I: Background Information

Date:	Start-end time:
Location:	
Respondent Name:	Title:
Participant Category: State/City Official:	
Tel. #:	Email:

SECTION II: Questions on Developments in LTC and the NY PCS Program**A. AGENCY****Organizational Structure of LTC in NY:**

1. What is the organizational structure of LTC at the state level? (What are the specific LTC departments and programs in NY both within and outside the Medicaid program? Include institutional and HCBS)
2. What are the goals of the LTC programs in general? Is there a goal for shifting services from institutional to HCBS care or has a balance between the two been achieved?
3. Who are the state officials responsible for the management of LTC?
4. Have there been any recent organizational structure changes to LTC in NY state?
5. What is the organizational structure of LTC at the local level?
 - Does it vary by county and by NYC boroughs?
 - How many programs provide LTC services at the local level?
6. Does NY have single-point of entry for HCBS and institutional care at the local level?
7. Who are the local officials responsible for the management of LTC?

Organizational Structure of the PCS program:

8. What state programs offer personal care services in NY (e.g. waivers, HH, OAA)?
9. Who are the state officials responsible for each PCS program, including the state PCS optional program?
10. Describe the features of the PCS state plan program agency-delivery model.
11. Describe the features of the PCS consumer-directed delivery model.
12. Who are the state officials responsible for these two programs?
13. When and why was the PCS consumer-directed model established? Are these programs separate and if so, why?
14. Have there been any recent organizational structure changes to the PCS program?

Coordination of LTC and PCS programs

15. How do NY LTC program directors coordinate at the state level? How often?

16. What is the communication and working relationships between LTC state officials?
 - Between State and local officials?
17. What are the communication and working relationships between PCS programs at the state level (i.e. state plan option, waivers, OAA)?
18. What are the communication and working relationships between PCS agency directed and consumer directed programs at the state level? At the local level?
19. What is the process by which HCBS program directors learn about each others services?
20. How do HCBS departments/ programs avoid duplication of services or serving the same clients?
21. Have there been any recent management changes with LTC in NY? In the PCS program?
22. Does the state currently have an advisory committee for the PCS program?

Olmstead Planning

23. Does NY have an Olmstead Plan in place in response to the Olmstead Decision?
24. If so, when was the plan completed and when was the last revision to the plan?
25. If so, who was involved in the planning? (How were consumers involved?)
26. If so, what has been accomplished in LTC in NY since the plan was made?
27. If so, how often is the plan evaluated and changes made in the plan?
28. Does the state currently have an advisory committee for Olmstead planning?

Financing the PCS Program

29. What is the state budget authorized for PCS care for the coming year? For the agency model and the consumer directed model?
30. Describe the financial arrangements for funding PCS in NY? Are programs financed by state and federal funding only or does it include county or local funding?
31. Have there been any recent changes in the funding of the PCS programs?

Cost Containment for the PCS Program

32. What cost controls are used for the PCS program?
33. What are the ceilings on hours authorized per participant for the program if any? (what period?)
34. What are the limits on total expenditures per participant if any? (what period)
35. Are there other limits to the program?

Quality Assurance/ Monitoring for the PCS Program

36. What departments and programs are responsible for the quality oversight of LTC programs in NY at the state level?

37. What programs are responsible for the quality oversight of the PCS state plan program at the state and local levels? (Including for PCS agency contractors?)
38. What minimum quality assurance requirements are built into PCS agency contracts?
39. Is there a state or local hotline for consumer PCS complaints or a PCS help line (when a worker calls in sick) available and who is responsible for these services?
40. Are there written guidelines for agencies handling of 'difficult to serve' clients?
41. Does the state conduct surveys of PCS participants regarding quality?
42. What happens in the case of abuse, theft or fraud in the PCS program?

Litigation and Appeals Process

43. Are there any current litigation cases against the state or local agencies in the PCS program?
44. How is the appeals process for denial of PSC or other PCS cases handled?

B. CLIENTS:

Informed Choice:

45. How does NY inform consumers about the availability and access to LTC programs?
46. What is the procedure for consumers to request a specific delivery model of PCS?
47. Is there a central registry of available agency providers for consumers to choose from? If so, who is responsible for managing the program? Is it at the state or local level?
48. How do consumers find workers if they request the consumer-directed delivery model?

Eligibility Criteria

49. What are the financial eligibility criteria for participation in the PCS program? (e.g. 100% of SSI, 150%, 300% or other)? Are the medically needy covered by the program?
50. Any recent changes in financial eligibility criteria? Are these different from the waiver programs?
51. What are the need criteria for participation in the PCS program? (e.g. number of ADL and IADL limitations, social need or other requirements)
52. Any recent changes in need eligibility criteria? Are these different from the waiver programs?

Assessment Procedures

53. Is a physician's order required to be assessed or receive PCS services?
54. What assessment instrument is used for the PCS program?
55. Is the same assessment instrument used uniformly throughout NY for all PCS programs?
56. Is the same assessment instrument used for all types of clients (i.e. Aged, Disabled, DD, TBI, etc.)?

57. Is the same instrument used for assessment in all the waiver programs?
58. Who does the assessment of the client? (Are there requirements such as being a social worker or a nurse or training for assessors?) (Does the agency making the assessment also authorize and/or provide services?)
59. Where is the assessment done? (i.e. hospital, home, nursing home, residential care, etc).
60. Have there been any recent changes in the screening/assessment tool used? Should there be changes in the future?
61. Does NY offer 'Fast Track' eligibility processing for LTC? If so, please describe the program.

Services Authorization

62. What are the guidelines for determining hours? Is this uniform throughout NY?
63. Who is responsible for determining the number of hours allotted to participants?
64. What are the education and training requirements for PCS supervisors and case managers?
65. What is the role of supervisors and case managers (CM) in the PCS program?
66. What is the ratio, on average, of CM to participants in the PCS program?

Location of PCS

67. At what locations can consumers receive care? (Home, residential care, work, school, other?)
Is this uniform throughout NY?
68. Are there any limitations on the location of services?

Services Available

69. What specific services can be provided in addition to assistance with ADL and IADL care?
Medical transportation, non-medical transportation, cuing, emergency support and respite, animal care, assistive technology, case management, tasks delegated by a nurse, other?

Consumer-Direction PCS Program

70. Describe the features of consumer-direction PCS program model in NY?
71. What are the differences in goals and program management between the PCS agency and the consumer directed programs?
72. Were consumers involved in the development of the consumer directed program and, if so, how?
73. What is the role of the consumer in the consumer-directed delivery program? How is this different than their role as a participant in the agency-delivery model?
74. Are consumers allowed to hire and fire their PCS workers in the consumer directed program and in the PCS agency program?

75. Are provider agencies required to have a consumer-direction component? If so, please describe.
76. Have there been any recent changes in how NY involves consumers in the PCS program?
77. Are consumers allowed to have independent providers in either the agency or the consumer directed program models? If not, why not?
78. Are family members allowed to be paid to provide PCS? If yes, describe the circumstances and any limitations.
79. If independent providers are allowed, who pays them (the state, agencies, public authorities, others?)

C. AGENCY PROVIDERS & PERSONAL CARE SERVICES WORKERS

Contracts & Reimbursement

80. How many PCS provider agencies provide PCS through contracts in NY State?
 - How many agency contracts are there currently in the agency model?
 - How many participants are receiving PCS via the agency-delivery model?
 - What type and number of agencies provide services in the consumer-directed model?
 - How many participants and providers are in the consumer-directed model?
81. How are contracts with PCS provider agencies awarded in the PCS program? Who makes the decisions?
82. Are there any restrictions on what types of programs can provide PCS such as Medicare certified home health agencies, centers for independent living, facilities that provide residential care, foster care, etc?
83. Do agencies providing PCS have to be licensed by the state and if so, what are the licensing requirements?
84. How is the number of contracts decided, and has this number changed over time? How often are contracts negotiated?
85. Are agency contract requirements uniform throughout NY for the PCS program?
86. What are the reimbursement rates to agencies and how is this determined?
87. When was the last increase in reimbursement rates to agencies?

Wages & Benefits

88. How are wages and benefits determined for the PCS program? Do these vary by county and NYC borough?

89. What is the current minimum wage rate paid to PCS workers? (By county and borough?)

90. Are agencies required to provide benefits to workers and, if so, what are they?

- (e. g. health, vacation, workman's compensation)? Are these uniform across counties and NYC boroughs?

91. How many and which unions are involved with the PCS program?

92. Describe the collective bargaining process with the unions and who negotiates and at what level (state or county). (Are all workers in the state unionized)? When did collective bargaining for the PCS program first start?

93. When was the last increase in wages to workers? Is this the same throughout NY State?

Labor Market

94. How many PCS workers are there currently employed in the program in each area of the state?

In the agency program and the consumer directed program?

95. Describe the current PCS labor market in the urban and rural areas of NY. Are there shortages of PCS workers? If so, are any special efforts being made to address this market?

96. How do agencies recruit workers?

Requirements for PCS Workers

97. Are criminal background checks required?

98. Is immigration status checked?

99. Are their written and speaking language requirements for the program?

100. What are the training requirements for workers in the PCS program?

101. Who provides the training for the workers and where is this done?

Evaluation of the PCS Program

102. What is your overall assessment of the PCS program in NY in terms of its structure, goals, management, and effectiveness?

103. What structure, policy, or administrative changes would you like to see made in the program?

104. What are the major barriers to improving access, quality or cost of the program?

SECTION III. ADDITIONAL INFORMATION

Is there anything else I should know?

Is there anyone else you think I should contact?

APPENDIX D: Study Questionnaire for Local PCS Agencies

SECTION I: Background Information

Date:	Start-end time:
Location:	
Respondent Name:	Title:
Participant Category: State/City Official:	
Tel. #:	Email:

SECTION II: Questions on Organization and Management**B. AGENCY****Organizational Structure of the PCS program:**

105. What local programs offer personal care services in your area (e.g. waivers, HH, OAA)?
106. Who are the local officials responsible for each PCS program, including the state PCS optional program?
107. Describe how your PCS agency is organized and who is responsible for the agency?
108. When and why was the PCS consumer-directed model established?
109. How does the PCS agency model differ from the consumer directed model? Are these programs separate and if so, why?
110. Have there been any recent organizational structure changes in the PCS program?

Coordination of LTC and PCS programs

111. How does your agency coordinate with other PCS and HCBS programs at the local level?
How often?
112. What is the communication and working relationships other LTC programs at the local level?
113. What are the communication and working relationships between PCS programs at the state level?
114. What are the communication and working relationships between PCS agency directed and consumer directed programs at the local level?
115. What is the process by which local HCBS programs learn about other services?
116. How do HCBS departments/ programs avoid duplication of services or serving the same clients at the local level?
117. What communication and coordination does your agency have with the state PCS program, if any?

118. Does your agency currently have an advisory committee?

Olmstead Planning

119. Does NY have an Olmstead Plan in place in response to the Olmstead Decision?

120. If so, how would you evaluate the plan and its impact on PCS?

121. How often is the plan evaluated and changes made in the plan?

Financing the PCS Program

122. What is your agency budget for PCS care for the coming year?

123. How is your agency budget determined each year?

124. Have there been any recent changes in the funding of the PCS programs?

Cost Containment for the PCS Program

125. What cost controls does your agency use for the PCS program?

126. What are the ceilings on hours authorized per participant for the program if any? (what period?)

127. What are the limits on total expenditures per participant if any? (what period)

128. Are there other limits to the program?

Quality Assurance/ Monitoring for the PCS Program

129. What minimum quality assurance requirements are built into your PCS agency contract?

130. Do you have a state or local hotline for consumer PCS complaints or a PCS help line (when a worker calls in sick) available and who is responsible for these services?

131. Are there written guidelines for agencies handling of 'difficult to serve' clients?

132. Does your agency conduct surveys of PCS participants regarding quality?

133. What happens in the case of abuse, theft or fraud in the PCS program?

Litigation and Appeals Process

134. Are there any current litigation cases against your agencies in the PCS program?

135. How is the appeals process for denial of PSC or other PCS cases handled?

B. CLIENTS:

Informed Choice:

136. How does your agency inform consumers about the availability and access to LTC programs?

137. What is the procedure for consumers to request a specific delivery model of PCS?

138. Is there a central registry of available agency providers for consumers to choose from? If so, who is responsible for managing the program?

Eligibility Criteria

- 139. What are the need criteria for participation in the PCS program? (e.g. number of ADL and IADL limitations, social need or other requirements)
- 140. Any recent changes in need eligibility criteria? Are these different from the waiver programs?

Assessment Procedures

- 141. Is a physician's order required to be assessed or receive PCS services?
- 142. What assessment instrument tool is used by your agency for the PCS program?
- 143. Is the same assessment used for all types of clients (i.e. Aged, Disabled, DD, TBI, etc.)?
- 144. Who does the assessment of the client? (Are there requirements such as being a social worker or a nurse or training for assessors?)
- 145. Where is the assessment done? (i.e. hospital, home, nursing home, residential care, etc).
- 146. Have there been any recent changes in the screening/assessment tool used?
- 147. Does your agency offer 'Fast Track' eligibility processing for LTC? If so, please describe the program.

Services Authorization

- 148. What are the guidelines for determining hours?
- 149. Who is responsible for determining the number of hours allotted to participants?
- 150. What are the education and training requirements for PCS supervisors and case managers?
- 151. What is the role of supervisors and case managers (CM) in the PCS program?
- 152. What is the ratio, on average, of CM to participants in the PCS program?

Location of PCS

- 153. At what locations can consumers receive care? (Home, residential care, work, school, other?) Is this uniform throughout NY?
- 154. Are there any limitations on the location of services?

Services Available

- 155. What specific services can be provided in addition to assistance with ADL and IADL care? Medical transportation, non-medical transportation, cuing, emergency support and respite, animal care, assistive technology, case management, tasks delegated by a nurse, other?

Consumer-Direction PCS Program

- 156. Does your agency required to have a consumer-direction component? If so, please describe.
- 157. What is the role of the consumer in the agency PCS program? How is this different than their role as a participant in the consumer-directed delivery model?

158. Are consumers allowed to hire and fire their PCS workers in the consumer directed program and in the PCS agency program? Can consumers change PCS workers when they want to?
159. What are the differences in goals and program management between the PCS agency and the consumer directed programs?
160. Have there been any recent changes in how NY involves consumers in the PCS program?
161. Are consumers allowed to have independent providers in either the agency or the consumer directed program models? If not, why not?
162. Are family members allowed to be paid to provide PCS? If yes, describe the circumstances and any limitations.
163. If independent providers are allowed, who pays them (the state, agencies, public authorities, others?)

D. AGENCY PROVIDERS & PERSONAL CARE SERVICES WORKERS

Contracts & Reimbursement

164. How are contracts with PCS provider agencies awarded in the PCS program? Who makes the decisions?
165. What are the agency contract requirements for the PCS program?
166. What are the reimbursement rates to agencies and how is this determined?
167. When was the last increase in reimbursement rates to agencies?

Wages & Benefits

168. How are wages and benefits determined for the PCS program in your agency?
169. What is the current minimum wage rate paid to PCS workers in your agency? What is the wage range and is there a ceiling?
170. Does your agency provide benefits to workers and, if so, what are they? (e. g. health, vacation, workman's compensation)?
171. Does your agency have union contracts? How many and which unions are involved with the PCS program?
172. Describe the collective bargaining process with the unions and who negotiates and at what level
173. When was the last increase in wages to PCS workers in your agency?

Labor Market

174. How many PCS workers are there currently employed by your agency?

175. Describe the current PCS labor market in your area. Are there shortages of PCS workers?

If so, are any special efforts being made to address this market?

176. How does your agency recruit workers?

Requirements for PCS Workers

177. Are criminal background checks required?

178. Is immigration status checked?

179. Are their written and speaking language requirements for the program?

180. What are the training requirements for workers in the PCS program?

181. Who provides the training for the workers and where is this done?

Evaluation of the PCS Program

182. What is your assessment of the PCS program in NY in terms of its structure, goals, management, and effectiveness?

183. What structure, policy, or administrative changes would you like to see made in the program?

184. What are the major barriers to improving access, quality or cost of the program?

SECTION III. ADDITIONAL INFORMATION

Is there anything else I should know?

Is there anyone else you think I should contact?

APPENDIX E: Stakeholder Questionnaire for Consumer Organizations, Unions,
and other Stakeholder Groups

SECTION I: Background Information

Date:	Start-end time:
Location:	
Respondent Name:	Title:
Participant Category:	
Tel. #:	Email:

SECTION II: Questions on Developments in LTC and the NY PCS Program

Background

1. Describe your organization and the people you serve.
2. How long has your agency/organization been involved in LTC in NY?
3. How do you interact with state and local officials responsible for LTC and the PCS programs?
4. Are you involved with any other stakeholder groups which meet and interact with state and/or local officials about LTC or the PCS program?

C. AGENCY

Organizational Structure of LTC in NY:

185. What is your opinion of the organizational structure of HCBS and PCS at the state and local levels? Are they too centralized/decentralized?
186. Is the PCS program integrated with other PCS and HCBS programs at the state and local level?
187. Are the HCBS and PCS programs too consolidated or dispersed at the state and local levels?
188. Does NY have single-point of entry for HCBS at the local level? Is this a goal of the LTC program?
189. What are the goals of the LTC programs in general? Is there a goal for shifting services from institutional to HCBS care or has a balance between the two been achieved?

Organizational Structure of the PCS program:

190. What is your view of the PCS state plan program agency-delivery model in terms of its goals and its organizational structure?
191. What is your view of the PCS consumer-directed delivery model in terms of its goals and its organizational structure?
192. Why was the PCS consumer-directed model established? What are the benefits and problems with this model?
193. Should the PCS program allow for independent providers? Please explain.

Coordination of LTC and PCS programs

194. How would you assess the communications and working relationships between state and local PCS programs and other state and local HCBS programs?
195. How would you assess the communications and working relationships between local PCS programs and your organization and other stakeholder groups?
196. What is your view of the PCS state plan program agency-delivery model in terms of its management and operations?
197. What is your view of the PCS consumer-directed delivery model in terms of its management and operations?
198. What are the communication and working relationships between PCS agency directed and consumer directed programs at the state level? At the local level?
199. How do HCBS departments/ programs avoid duplication of services or serving the same clients?
200. Does the state currently have an advisory committee for the PCS program? If not, would this be useful?

Olmstead Planning

201. Does NY have an Olmstead Plan in place in response to the Olmstead Decision? If so, when was the plan completed and when was the last revision to the plan? If not, why has hasn't the state developed one?
202. If so, who was involved in the planning? (How were consumers involved?)
203. If so, what has been accomplished in LTC in NY since the plan was made?
204. Does the state currently have an advisory committee for Olmstead planning?

Financing the PCS Program

205. Is the state budget authorized for PCS care for the coming year adequate? What about for the agency model and the consumer directed model?
206. Should there be changes in the funding of the PCS programs?

Cost Containment for the PCS Program

207. What cost controls are used for the PCS program? (e. g. limits on hours or expenditures?)

208. How would you evaluate the PCS program cost controls? Are they effective?

Quality Assurance/ Monitoring for the PCS Program

209. Is the quality oversight for the PCS state plan program at the state and local levels adequate?

- Is there a state or local hotline for consumer PCS complaints or a PCS help line (when a worker calls in sick) available and who is responsible for these services?
- Does the state conduct surveys of PCS participants regarding quality?
- What happens in the case of abuse, theft or fraud in the PCS program?

Litigation and Appeals Process

210. Are there any current litigation cases against the state or local agencies in the PCS program?

211. How would you evaluate the appeals process for denial of PSC or other PCS complaints?

B. CLIENTS:

Informed Choice:

212. How effective is NY in informing consumers about the availability and access to LTC programs?

213. Are the procedures for consumers to request a specific delivery model of PCS adequate?

214. Is there a central registry of available agency providers for consumers to choose from?

215. How do consumers find workers if they request the consumer-directed delivery model?

Eligibility Criteria

216. Are the financial eligibility criteria for participation in the PCS program adequate?

217. What is your evaluation of the need criteria for participation in the PCS program?
Should these be changed?

Assessment Procedures

218. What is your view about the assessment instrument used for the PCS program?

219. Is the same assessment tool used uniformly throughout NY for all HCBS programs and for different client types? If not, should it be the same?

220. Does NY offer 'Fast Track' eligibility processing for LTC? If not, should it have one?

Services Authorization

221. What is your assessment of the PCS authorization process?

222. Are the education and training requirements for PCS supervisors and case managers adequate?

223. Is the ratio, on average, of CM to participants in the PCS program adequate?

Location of PCS

224. Should there be any change in the locations where consumers receive PCS care? (Home, residential care, work, school, other?)

Services Available

225. Should there be changes in the specific services provided in the PCS program? (Medical transportation, non-medical transportation, cuing, emergency support and respite, animal care, assistive technology, case management, tasks delegated by a nurse, other?)

Consumer-Direction PCS Program

226. What are the differences in goals and program management between the PCS agency and the consumer directed programs?

227. Are consumers allowed to hire and fire their PCS workers in the consumer directed program and in the PCS agency program?

228. Are provider agencies required to have a consumer-direction component? If so, please describe.

229. Have there been any recent changes in how NY involves consumers in the PCS program?

230. Are consumers allowed to have independent providers in either the agency or the consumer directed program models? If not, why not?

E. AGENCY PROVIDERS & PERSONAL CARE SERVICES WORKERS

Contracts & Reimbursement

231. What is your assessment of the PCS provider agencies contracts and the contracting process at the local level?

232. Are agency contract requirements sufficient to ensure access and quality in the PCS program?

233. Are the reimbursement rates to agencies adequate?

Wages & Benefits

234. Are the current minimum wage rate paid to PCS workers adequate? (By county and borough?)

235. Are the benefits to workers adequate (e. g. health, vacation, workman's compensation)?

236. What is the impact of the unions involved with the PCS program on PCS quality, cost and access?

Labor Market

237. Describe the current PCS labor market in the urban and rural areas of NY. Are there shortages of PCS workers? If so, are any special efforts being made to address this market?

Requirements for PCS Workers

238. Are the requirements for PCS workers adequate (e.g. criminal background, immigration status, written and speaking language requirements, and training requirements?)
239. Are changes in the amount and type of training needed and in who provides the training for the workers?

Evaluation of the Program

240. What is your overall assessment of the PCS program in NY in terms of its structure, goals, management, and effectiveness?
241. What structure, policy, or administrative changes would you like to see made in the program?
242. What are the major barriers to improving access, quality or cost of the program?

SECTION III. ADDITIONAL INFORMATION

Is there anything else I should know?

Is there anyone else you think I should contact?

APPENDIX F: Documents for Data Analysis

Organizational Structure: LTC

- List of all LTC Departments
- Organizational Charts for the Department of Health
- Organizational Chart for the Office of Medicaid Management
- List of Social Service Agencies by County (AAAs)
- List of Waivers (e.g. Aged, MR, DD, TBI)

Organizational Structure: PCS Program

- Organizational Chart for the PCS Program
- List of State Officials responsible for the PCS Program
- List of Local/County Officials responsible for the PCS Program

Olmstead Planning

- Olmstead Plan for NY
- Coalition to Implement Olmstead in NY (CTIONY) Report

Financing the PCS Program

- Federal/State funding regulations/ guidelines
- NY PCS Program Budget (over time)

Cost Containment: PCS Program

- Regulations on program limits
- Regulations on authorization procedures

Quality Assurance/ Monitoring: PCS Program

- Information on the hotline for PCS consumer complaints
- Sample Surveys to PCS participants for quality oversight

Informed Choice: PCS Program

- Written information on option for agency vs. consumer-directed model of PCS
- Documentation on a central registry for providers?

Eligibility Criteria: HCBS and the PCS Program

- Financial Criteria Regulations
- Need Criteria Regulations

Assessment Procedures

- Assessment Tool(s): HCBS and PCS

Services Authorization: PCS Program

- Guidelines for determining hours of PCS (NYC and “upstate”).
- Education/Training Requirements for PCS supervisors/ case managers.
- Regulations on types of services provided in addition to PCS.
- Regulations on location(s) of where PCS may be provided.

Consumer-Direction: PCS Program

- CDPAP Regulations
- Document: Q & A about the CDPAP (distributed May 2006 from the state)

Contracts & Reimbursement: PCS Program

- State regulations on contracts, procedures and requirements
- Sample contract between state and agency providers
- Sample contract between state and CDPAP providers
- Licensing Requirements for CDPAP providers
- List of types of providers that can offer the CDPAP model
- List of contracts by county
- List of providers by contract type (agency, CDPAP)
- Reimbursement Rates to Agencies

Wages & Benefits: PCS Program

- Documentation on minimum wage in US and NY
- Wage variation in NY by county. By “upstate” vs. NYC.
- Benefits:
 - Health
 - Vacation
 - Worker’s Compensation
- List of all Unions involved with the PCS Program by area
- Sample Collective Bargaining Agreement in NYC

Labor Market: PCS Workforce

- Training Requirements
- Sample Training Materials
- Regulations for Criminal Background Checks
- Samples of Workforce Recruitment Materials

UCSF Personal Assistance Services (PAS) Center

- Documents on the NY PCS Program, 1999-2005

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