

**CONSUMER DIRECTED PERSONAL ASSISTANT CARE:  
AN INQUIRY INTO PROGRAMMING FOR ELDERLY COGNITIVELY  
IMPAIRED**

**By**

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**INTRODUCTION**

There is a quiet revolution underway in long term care for the chronically ill and chronically disabled. It is nothing less than a major shift in how the ancient doctrine of *parens patriae* is played out for children, people with mental illness, people with mental retardation people with physical disabilities and the elderly disabled. The force and direction of this revolution are not diminished by the fact that it has been brewing for a generation.

This chapter concerns itself with the elderly and how American decision-makers are incorporating, increasingly, concepts of self-determination, autonomy, and independence, and moving away from the traditional paternalism exemplified by past reliance on institutional care. The changes are, by no means, uniform across the entire population of vulnerable elderly. There are significant differences depending upon the nature and etiology of the disability, the presence and availability of surrogates and advocates, the availability of a wide range of support services, the quality of available housing, and the particular history and characteristics of local public support, notably Medicaid.

This chapter explores the attitudes and experiences of surrogates during the first year of a three year demonstration project conducted in New York City. The purpose of this consumer directed personal care attendant service project was to test the utility of "a supportive intermediary" in assisting surrogates to secure personal assistance in home-

based care for elderly people with cognitive impairments. While the findings are limited to the first year they are instructive, at least for a major urban jurisdiction offering generous benefits, about some of the complexities program advocates for consumer directed programs for the elderly confront. These findings include perceptions about the Medicaid program and interdependencies among needed services and programs. Given the considerable attention and efforts currently focussed on consumer directed programs and policies, these early findings may be important beyond their quantitative limitations.

### **Ethical Underpinnings**

The evolution of consumer directed services is the latest logical step as our Human Services system emerges from several hundred years of English tradition. The current demonstrations and relatively few programs of “Cash and Counseling”, “Consumer Directed Personal Care”, and other consumer oriented programs for people with disabilities are the direct progeny of initially narrowly construed doctrines of *parens patriae* (Horstman). *Parens patriae* holds that those who are unable to fend for themselves and have no one to care for them are the responsibility of the sovereign. In its earliest iterations it included paupers, “idiots”, the insane, orphans, widows, “victims of Indian raids”, the aged, disabled veterans, the chronically disabled, etc.

This evolution is grounded in the ethical principle of Respect for Persons, the ethical basis for expanded autonomy---expanded decisional choice (Collopy).

Probably the twentieth century's most significant step in the direction of greater autonomy for those deemed to be a responsibility of the sovereign (the state) under the *parens patriae* banner came with the passage of the Social Security Act. Among other things, the Act required states to provide *unrestricted cash grants* to poor persons

receiving public assistance through any of the public assistance titles of the Act (See, for example, 42 U.S.C. 306 governing Old Age Assistance). These provisions incorporated into law the ethical principles of Autonomy and Respect for Persons. They rejected the time honored idea that the sovereign could protect assistance recipients from poor economic decisions by giving them scrip redeemable only for food or rent, or even providing the service as in the poorhouse. Indeed, the Social Security Act expressly *disfavored* “indoor relief”, i.e. institutional care, excluding expenditures for "indoor relief" from federal reimbursement.

In the arena of mental illness, developmental disabilities, and institutional care for those with psychological and cognitive disabilities, the expansion of the principle in application has been articulated in legal terms as a requirement for the “Least Restrictive Alternative”. However, more recent analysis suggests that simply providing the Least Restrictive Alternative may become an excuse for neglect (Cohen 1985, Childress 1982) --an accusation that has its basis in what some have seen as “dumping” of perhaps hundreds of thousands of mentally ill persons from mental hospitals on to the streets and heating grates of America’s cities.

Consumer-directed service for the cognitively disabled represents a giant step in the evolution of applications of the principle of Respect for Persons in the human services. In the New York City program, the judgement of the sovereign is not replaced by the judgement of the individual (since by definition the individual has lost much capacity for judgement) or by a judicially appointed guardian, but rather by the judgement of a *surrogate*---one who can take on the responsibility for decision making,

and who will exercise judgment, presumably, in the best interests of the person with a cognitive disability.

But what principles guide that judgement---Beneficence/non-maleficence? Distributive Justice, i.e. a fair distribution of burdens and benefits? Truth-telling? Fidelity, i.e. the keeping of promises? Surely all of those! However, it is respectfully suggested that, given the all-encompassing impact of cognitive disability and the enormous variety of factors that affect how that impact is processed by the disabled individual, the guiding principles should be those incorporating anticipated *outcomes* for the person with the disability. This, we believe, requires a postulate we would term *The Most Liberating Alternative*.

The most liberating alternative is that which provides the greatest degree of freedom in all salient elements of the individual's life. Sometimes this may correspond perfectly with the principle of the Least Restrictive Alternative, but not always.

The least restrictive alternative as applied to the chronically ill or disabled, one might argue, is that which is most free from physical restraint. For a person with quadriplegia, freedom from all restraint would, in fact, confine the individual to bed. Conversely, securely restrained in a "puff and sip" elevating motorized wheelchair, the individual could not only travel about, but could do so in postures that yielded equality, proxemically speaking, in ordinary social engagement. For people with cognitive impairments, application of the least restrictive alternative in conventional terms might produce an environment that might induce panic in the "lost" individual who wandered from a more contained and restricted area.

Thus, in-home service provided at the direction of a surrogate *may* be the most liberating alternative to in-home service provided at the direction of an agency, or to living in an assisted living facility, personal care home, or nursing home. But it is not necessarily so in all cases. In some situations living with surrogates may mean living in desperately overcrowded circumstances with little opportunity for privacy or for participation in community activities. Living with a surrogate, or a personal assistant in the absence of a working surrogate, in some circumstances may mean never being able to leave the dwelling, and living in circumstances which impose restrictions on stimulating social, psychological, and physical responses. Living in admittedly dangerous urban public housing projects can be a constraining environment which no amount of consumer directed care can overcome.

Judgements about surrogate directed care require special attention to anticipated outcomes and the conditions that attend the likelihood of achieving such outcomes. Such judgements are not arrived at with mathematical certainty based upon quantitative measurements and attainment of this or that score on some “Most Liberating Alternative Scale” or “Minimum Data Set”. Such judgements are grounded rather in the soft calculus of human behavior, environmental psychology, social psychology, and family psychology informed by hundreds and thousands of encounters with people with dementing illnesses and their families as they wrestle with problems of surviving and coping in the urban environment. Moreover, these encounters involve almost innumerable combinations and permutations of social, economic, and physical circumstances.

Neither the ongoing processes nor the policies behind the movements toward community based services, consumer choice, and consumer direction are linear, defined in "black and white" terms, or predicated in present law. Rather, the quiet revolution is grounded in what is, for the elderly, an evolving ethic.

Essentially and simply stated, the issue concerns where and how elderly persons requiring long term care, because of physical and/or cognitive disability or illness, ought to be cared for and whether that care should be at public or private expense. Even further, it requires extending the right to flourish---a right which pushes the principle of Respect for Persons---to those too often regarded as incapable of "flourishing": people with cognitive disabilities, mental retardation or dementia.

To a limited extent, the issue has been resolved in a significant number of jurisdictions in the U. S. for people with developmental disabilities, mental retardation, the non-elderly mentally ill and young people with chronic physical disabilities. This is not to say that the resolution has produced uniformly satisfactory outcomes. Indeed, the contrary is closer to the truth. All over America the deinstitutionalization of the mentally ill has resulted in the younger population being shifted to the community without much support and the elderly mentally ill being "trans-institutionalized" into nursing homes and similar long term care facilities. In some contrast, however, the institutionalized people with developmental disabilities and mental retardation have moved into a wide variety of supported community settings ranging from independent living to intermediate care facilities for the mentally retarded (ICF-MR), and the younger population of people with chronic physical disabilities have moved into a range of community facilities (including independent living). These community placements have been accompanied with a wide

range of supportive services provided by education, transportation, health care, recreation and other "systems" at the community level. Nonetheless, too many (particularly those with severe physiological disorders and mental retardation, often referred to as dual-diagnoses,) have been shifted into long term care facility arrangements.

### **Issues for the Elderly**

The issues for the elderly are complex. They involve matters grounded in traditional American attitudes about the place of the elderly in American Society (Lerner 1957, Butler 1975), the attitudes the elderly themselves have adopted about old age (Cohen 1988), application of teleological rationales applied to geriatric illness and disability, cost factors, and sheer demographic growth among the oldest old, and hence, those most likely to require extensive, if not necessarily complex or high-tech care.

The issue is further confounded by the huge investment in institutional real estate (roughly valued at \$100 - \$125 *billion*) and the consequent interest of banks and investors. In addition, the interests of organized labor in retaining employment in institutions have presented vigorous political obstacles to reform. And finally, there is the very real concern about the potential of abandoning the chronically ill and disabled in the guise of granting "autonomy" (Childress 1982, Cohen 1985).

In some jurisdictions, superimposed upon these special considerations in consumer directed personal care assistance for the elderly, is the issue of just what services non-professional personal assistants may provide within the limitations of so-called "Nurse Practice Acts" (Johnson 1999). Such acts ostensibly prohibit a non-professional personal assistant from providing care, medications or administering certain medical tests designed for *self*-administration. Examples include catheter care,

gastrostomy tube care, ventilator care, tracheotomy care, glucose level testing, and administering medications.

The issue of nursing home care vs. community based care has been raised time and again over the last 35 - 40 years. It has most recently been raised in the legislative and judicial arenas with the introduction of SB1935 (106<sup>th</sup> Congress), The Medicaid Community Attendant Services and Supports Act of 1999 (MiCASSA) by Senators Tom Harkin (D-IA) and Arlen Specter (R-PA), and the holdings of the Supreme Court in *Olmstead v. L.C.* 98-536 (1999).

Within the general policy debate and activity about in-patient long term care vs. community based care there are additional considerations about the *nature* of community based care (e.g. structured home-maker services, nutrition services in center-based soup kitchens or through home delivery, specified professional in-home nursing care services, organized home medical care, and personal care attendant services) as well as the issue of control over services, i.e. *consumer*-directed services vs. *agency*-directed services versus *hybrid consumer directed/fiscal agency* supported services. Finally, there are further confounding issues that arise when the subject population is cognitively impaired *and* the natural history of the disease/disability is characterized by on-going decline and degradation of cognitive capability, with its resultant increased reliance upon surrogates for decision-making.

### **The Legal and Regulatory Framework for Home-Based Care, Personal Assistant Services, and Consumer Directed Care**

Home-based care, personal assistant services, and consumer directed care have been common among the well-to-do since our earliest history. Although limited, such arrangements persist (Morris et al 1999). In the United States and England, institutional

care in the form of the publicly funded work-house, almshouse and poorhouse, by whatever name known was the common early instrument of care for the indigent chronically ill and disabled of all ages (Komisar 1973, Schneider and Deutsch 1941, Tollen 1964). Those who were not indigent were cared for by family members. In the case of the wealthy without family, the individuals themselves or their guardians purchased the necessary care that was provided in the home. This pattern of responsibility persisted from Colonial times into the mid-nineteenth century when private charitable and eleemosynary institutions, special public hospitals for the insane (sic), and facilities for mentally retarded emerged upon the American landscape.

Typically, charitable and eleemosynary facilities served the indigent affiliated by religion, gender (e.g. widows), geography, or veteran status. Private for profit long term care appeared on the scene in the third decade of the twentieth century, and became a dominant form of chronic disease and disability care for the indigent and non-indigent elderly throughout the last half of the century. It was during this period that major public supports for such care became available not only to the indigent, but also to the *medically* indigent as a result of the passage of Social Security Act Amendments creating Title XIX (42 U.S.C. Ch. 7 Subch. XIX). In addition, significant fiscal resources became available to long term care facility developers following the legitimization of nursing homes as an investment through amendments to Federal Housing Administration mortgage insurance programs (12 U.S.C. 1715w(a)(1) nursing homes, (2) intermediate care facilities).

During the last decade of the century, there appeared a new set of group residential arrangements, Assisted Living Facilities, targeting the physically and

cognitively disabled elderly. Federal mortgage insurance has been extended to this group as well (12 U.S.C. 1715w(a)(3) assisted living facilities for the frail elderly.

Public financing also underwent significant change. The Omnibus Reconciliation Act (OBRA) of 1993, 13601(a)(5) added Sec. 1905(a)(24) to the Social Security Act to include payment for personal care services within the definition of “Medical Assistance”. Harrington et al (1998) provides a thorough review and analysis of federal Medicaid statutes and regulation comparing the personal care program, the home and community based services waiver program, and home health program to institutional care. The report is written from a perspective of maximal choice of care and services by people with disabilities, examining program services which enable people to live in the community rather than institutions, program arrangements offering the least restrictive alternative, and program efforts which enable individuals to achieve or maintain self-sufficiency and economic support and to prevent dependency.

The statutory revisions and the subsequent regulatory changes provided very significant options for states regarding federal reimbursement for personal care services. The new regulations at 42 CFR 440.167 et seq provided for personal care services furnished in any setting other than inpatient hospitals, nursing care facilities, intermediate care facilities for the mentally retarded or mental institutions. Personal care services could be furnished within or outside a person’s home. Such services were significantly “de-medicalized”, requiring neither prescription by a physician nor supervision by a professional nurse. Services include a wide range of activities of daily living (ADLs) and instrumental activities of daily living (IADLs) which include more complex life activities.

Furthermore, personal care assistance for persons physically able but cognitively impaired was included. States embracing the Personal Assistance Care Option are permitted to employ a consumer-directed model for those individuals not cognitively impaired, although it appears that surrogates can qualify under the option.

States are given wide latitude in regulating such programs to assure receipt of quality services, including establishment of minimum requirements for personal assistants, underwriting costs of training of such assistants, complaint and grievance management, oversight and monitoring services and other quality control devices.

The New York City Supportive Intermediary Project sponsored by the Alzheimer's Association, New York City Chapter addresses the needs and desires of families and/or other surrogates providing and managing Personal Care/Home Attendant programs furnished through the Consumer Directed Personal Assistant Program (CDPAP) of the New York State Medicaid Program to or in behalf of persons with Alzheimer's Disease or other dementing illnesses. The CDPAP program allows eligible consumers or their surrogates to recruit, hire, train and dismiss their home care workers. Financing is underwritten through the Medicaid program which is administered in New York City by the Department of Human Resources.

The CDPAP is a component of a larger program of Home Care Attendant services financed through Medicaid. The Home Care Attendant Program is the largest of three parallel home care services programs provided by the City. As of September 30, 1998 there were 44,624 cases. In addition to the Home Care Attendant Program, there is the Home Care Services - Housekeeper program (7,250 cases) and the Long Term Home Health Care Program, also referred to as the "Lombardi" cases (8,306 cases) which

include a variety of special services such as nutritional counseling, social services counseling, etc.

The vast bulk of Home Care Attendant Services is provided through vendor agencies which furnish services to physically and cognitively disabled persons. The agency-provided services are directed by approved vendor agencies which hold contracts with the DHR. Agency provided services are directed by agency personnel which recruit, hire, train, and assign home care attendants to individuals with disabilities whose eligibility has been determined. The agencies set the schedules within the approved limits, select the home care attendants, and supervise the work of the attendants.

In CDPAP, the attendants are selected, trained and supervised by the person with the disability or a surrogate. Payment of attendants is handled through Concepts for Independence, Inc. (hereinafter, Concepts). Concepts serves as the fiscal intermediary for CDPAP. Utilizing Concepts as the fiscal intermediary makes it possible to provide attendants with a range of employee benefits including Social Security, Health benefits, Worker's Compensation Benefits, and Unemployment Insurance Benefits. In addition, it relieves consumers (and/or their surrogates) of the tasks of payroll administration, IRS and State Revenue Department filings, and the record keeping associated with employee benefits, while giving consumers and their surrogates control over recruitment, selection, training, supervision and scheduling of attendants. Consumers and their surrogates are, however, responsible for maintaining and submitting basic time-keeping records.

#### The Historical Roots of the Supportive Intermediary Project

The Supportive Intermediary Project has its roots in the substantial history and trends of social and health programs of the second half of the twentieth century---the

development of health care services for the poor and medically indigent, the Independent Living Movement, the closing and depopulation of institutions for the mentally ill and mentally retarded, and the rise of the nursing home as America's new mental institution.

In broad brush strokes, one might say that New York City's program evolved in three significant stages: Stage one---the emergence of health services for the poor and medically indigent under Title XIX (Medicaid) of the Social Security Act beginning in 1965 which had been preceded by "Medical Assistance for the Aged" two years earlier; stage two---the depopulation of America's State Mental Hospitals followed by closings of State Schools for the Retarded. This stage grew out of the development of the psychotropic drugs, the concomitant substantial Community Mental Health Movement, and a little later the significant court cases holding that large state institutions for the developmentally disabled were counter to the interests of developmentally disabled persons, and the development of community services for people with retardation; and finally, stage three---the period of the 1980's to the present time during which the Independent Living Movement emerged trumpeting consumer directed community based services, first for severely involved physically disabled persons, and subsequently for developmentally disabled persons.

The present project of the supportive intermediary for persons with dementia grows out of this history, and is a logical extension of what has gone before. In New York City, at least, it is an innovation in a program which heretofore had served only persons with physical disabilities who had the capacity to direct their own care. It is more complex than the predecessor programs providing for consumer direction. Its complexity is parallel to that presented in the consumer direction programs for persons with

developmental disability in its reliance on surrogate decisionmakers making decisions in behalf of the disabled person.

### **The Medicaid Home Care Personal Assistant Program**

The Home Care Personal Assistant Program is a highly structured program designed to provide Personal Assistants in one's own home financed in New York State by Federal, State and local funds for those persons who meet financial and health care eligibility standards under a set of state determined standards. The program is statewide in application and is an integral part of the State's Medicaid Program. That is to say, that the program is *not* one authorized under waiver rule.

Under the original structure of Medicaid, participating states were required to include in their state plans certain mandated services. However, states were permitted to include "optional" services for eligible participants and for which they would be reimbursed. For both mandated and optional services there were no financial or caseload caps. Subsequent amendments to Title XIX of the Social Security Act (Medicaid) permitted states to apply for waivers from recipient eligibility requirements of medical necessity for Medicaid reimbursement to the state. Under such waivers states providing certain "non-medical", social and other services to persons who might otherwise require medically oriented services such as long term care could be reimbursed for their expenditures on the theory that otherwise nursing home care or other "medical" utilities would be required. Federal reimbursement was (and continues to be) available for such

services even though they are not "medical" in the conventional sense. However, "waiver programs" have either or both financial and caseload caps.

The New York City Home Care Personal Assistant Program, being an integral part of the regular Medical Assistance program, is not subject to caseload or financial caps. This is an important feature which distinguishes the New York City program from most others, which are "waiver programs".

The high degree of structure grows directly out of the history of the Home Care Personal Assistant program in New York City. In or about the mid 1970's, home care, which had been treated almost as an exception to policy governing long term care, began to grow substantially. Home care was used increasingly as nursing home populations grew. In addition, the nursing home scandals of the late '60's and early 70's propelled the utilization of Home Care.

The Home Care program was decentralized into about 40 of 59 community districts throughout the five boroughs. *Social assessments* were carried out in the community district offices; *medical eligibility* was determined in the Medicaid Office at the Department's 16<sup>th</sup> Street office, while financial eligibility was determined in the Department's 34<sup>th</sup> Street office. When all the clearances were received the Department signaled a roster of people desiring to become home care attendants or notified the applicant for Medicaid-supported Home Care to employ someone if they had a contact. Payments were made directly by the then Department of Welfare by checks made out to both the recipient of the care and the home care attendants.

The program was, *in effect*, almost entirely consumer directed. There were few, if any, structural or quality control mechanisms in place as there are today to prevent

fiscal abuses. Furthermore, the city's role appeared to be limited to issuing the checks made out to both the attendant and the consumer. For all intents and purposes, consumers (or their families) hired and fired attendants, determined their qualifications, and reviewed their performance.

Review by the U.S. Department of Health and Human Services concluded that the program was essentially without adequate safeguards against abuse and notified the City that it would regard all home care attendants as city employees unless the program significantly clarified their status. In the late 70's and early '80's, the city "vendorized" the program, advertising for and ultimately contracting with about 70 agencies to provide home care attendant services.

When the Home Care Services Program was reorganized at the insistence of the federal government, consumer directed programming was not an option at the time. As noted below, when Consumer Directed programming *did* come into effect it was limited to people with *physical* disabilities. Persons with *cognitive* disabilities were not eligible, since by definition, it was reasoned, they could not be self directing nor could they take responsibility for the variety of tasks involved in recruiting, employing, training, and directing home care staff.

Furthermore, there was a severe barrier to serious expansion of home care, and hence consumer directed care, by virtue of the prohibitions in the Nurse Practice Act against certain procedures (e.g. bladder irrigation, administration of medications, mucous suction, etc.) being carried out by persons not licensed as either a professional nurse (i.e. Registered Nurses [RN]) or a Licensed Practical Nurse [LPN]). That barrier was also preventing care to the cognitively impaired. A 1992 amendment to the Nurse Practice

Act opened up the possibility of home care attendant services to severely involved physically involved individuals by non-licensed nursing service personnel, i.e. home health aides. Furthermore, that made possible major expansion of Concepts' services, which, among other things, were very efficient and very cost effective from the City's perspective.

### **Current Organization and Administration of the Home Care Program**

The reorganization brought about by the federal pressure resulted in considerable administrative consolidation. At the present time, except for decisions regarding Consumer Directed Care, the program is decentralized to 11 Community Alternative Service Agencies (CASAs) instead of 59 districts. CASAs are part of the local Department of Social Services (now the Human Resources Administration). Decisions regarding Consumer Directed Care are centralized to the Office of Home Care Services, and *all* applications for Consumer Directed Care flow across a single desk.

As of September 30, 1998 there was a total of 60,180 Home Care Services Cases on the books. These included the Home Care Personal Assistant, Housekeeper, and "Lombardi" cases which are grouped together in the Home Care Services Program Activity Report of September 30, 1998.

Of these, fewer than 1,000 were Consumer Directed!

It should be noted that consumer directed home care for persons with cognitive disabilities did not become part of the program until 1997. Public funding followed a small locally funded demonstration and the subsequent funding of the present demonstration under the Independent Choices Initiative of the Robert Wood Johnson Foundation. which is directed at what role, if any, a "supportive intermediary" plays in

enhancing access and utilization by elderly persons with cognitive disabilities and their surrogates to the public programs providing consumer-directed personal assistant care.

By any measure, New York City's Home Care Services Program is substantial. Not counting the "Lombardi" cases which account for expenditures of \$156,400,000, the total expenditures for the Home Care Attendants and Home Housekeepers for the fiscal year 1998 amounted to \$1,106,000,000---the total of federal, state and local expenditures.

Eligibility determination for Home Care services is highly structured. The process, eligibility standards, and levels of service are spelled out in exquisite detail in Sections 505.14 et seq of the Department of Health New York City Code of Rules and Regulations. The rules govern both the Home Attendant and Housekeeper components of the Home Care Services program. Without doubt, these detailed procedures were developed in response to the virtually unregulated approach of the 1970's and the subsequent requirements for fiscal and eligibility accountability imposed by state and federal agencies supervising the Medicaid program.

Applications from the community, i.e. from persons living in their own homes or with friends or relatives are initiated in the eleven CASAs. Upon first inquiry for information, and following an explanation of the program, the family or other surrogate for a person with Alzheimer's or other dementing illness are given a Medical Request for Home Care form (M-11q) to complete. The form is filled out by the individual's physician and is returned to the CASA. Upon return of the form, the surrogate is called and interviewed by telephone to determine if the individual is already qualified for Medical Assistance. If the applicant is not already qualified, the interviewer explains what a financial eligibility review will entail. It was reported that about 20 percent of

applicants who have returned the M-11q drop out at this point. It was also reported that people drop out for a variety of other reasons: some people may be hospitalized, some may elect to enter long term care facilities, some die, and some decide that they do not want to disclose the extent of their assets and income, or if they are eligible for partial assistance decide that they do not wish to participate. In order to handle the variety of cases at this stage and assure that the highest quality of counseling takes place, special intake staffing (pending units) has been established.

Following the M-11q and the telephone interview, an appointment is made for a home visit to complete a Home Care Social Assessment (M-11s) and a Nurse's Assessment Visit Report (M-11r). The M-11s is completed by CASA staff. The M-11r is completed by an outside agency with which the Department has a contract for the conduct of the Nursing Assessments.

The three assessment forms are then sent to a Medical Review Team for review and determination of the number of hours of home care service which will be approved. In the case of agency directed service, a vendor agency providing service in the geographical area in which the applicant is located is notified of the date on which service is to be initiated and the services which are to be provided. That triggers a visit by the agency nurse to review the situation and determine who is to serve that particular client. Following that visit, service is initiated.

In the initial interview, Department policy requires that the Consumer Directed option be presented. This requirement may be honored in the breach. Both Department personnel and surrogates interviewed indicated that information about consumer direction is not often offered. Whether offered by Department staff or sought by surrogates,

ultimately information is collected on The Consumer Directed Personal Assistance Program Application (M13d). This form, in addition to identifying information about the consumer and his/her surrogate, sets forth, in brief, the living arrangements and plans for recruitment, screening, training, directing, and monitoring the personal assistants as well as plans for emergency and back-up arrangements.

While a formal interview may or may not be scheduled with the caseworker in the CASA dealing with the individual, in fact there has been some verbal interchange to assist in the completion of the M13d, sufficient to warrant its transmission to and review by one key person in the central office of the Home Care Program. While review by a single designated individual within the central office may be viewed as an extraordinary constraint or as a potential bottleneck, the procedure was established deliberately to assure a high level of consistency and quality assurance on all reviews of requests for consumer directed care approvals. Furthermore, it provides an opportunity for a follow up interview with the consumer/surrogate seeking approval for self-directed care. This interview is based upon the M13d and generally goes over the nature of the consumer/surrogate role. For some applicants, this may be discouraging. The substantial tasks of the consumer/surrogate are reviewed---recruitment, training, supervision, regular contact, oversight and visitation as set out in the Concepts requirements described below. It is the reality check, particularly for surrogates who may have unrealistic expectations for the home care attendant.

Given the earlier history of Federal scrutiny and potential determination by the

U. S. Department of Health and Human Services that consumer directed personnel were, in fact, city employees, (not to mention the potentials for abuse or perceived abuse) it is understandable how this procedure came into being.

The process for persons coming from hospitals is different and may explain why that group, at least, may have even less of a chance to learn about consumer directed care than those coming from the community. When a hospitalized patient is getting ready for discharge and home care is being contemplated, the hospital social worker calls directly to the Office of Home Care operations to determine eligibility for Medicaid. Upon receiving clearance for Medicaid and receiving an authorization code, the hospital contacts a visiting nurse service, conveys the notice of authorization and initiate the patient's return to his/her home with a home health aide. Upon picking up the case, the visiting nurse serve contacts the Home Care Services program to initiate a "conversion process", i.e. converting the case from hospital care to Home Care. The case does *not* go through the "CASA process", and as a result the patient or his/her family is unlikely to be notified of the Consumer Directed Option, with it's referral to the fiscal intermediary for such, Concepts of Independence (hereinafter Concepts).

### **The Impact of Civil Rights Developments.**

In addition to changes in financing long term care in the 1960's, extraordinary civil rights protections were enacted for persons with disabilities about a generation later. The Americans with Disabilities Act of 1990 (ADA)(42 U.S.C. 12101 et seq) not only proscribes discrimination in the provision of public services but also directs the Attorney General to issue regulations implementing the proscription. Under the issued regulations, public entities are required to “. . . administer . . . programs . . .in the most integrated

setting appropriate to the needs of qualified individuals with disabilities(28 CFR 35.130(d). The term “integrated setting” is used in distinguishing it from a “segregated setting”, viz. an institutional setting. Thus, community-based programming has received something more than the sanction provided under the Social Security Act provision permitting states to provide community-based long term care. While the act appears to have had greatest impact on younger individuals, there is no gainsaying the potential impact on the elderly as well.

Furthermore, the recent opinion in *Olmstead v. L.C.* (U. S. Sup. Ct. (98-536) 138 F.3d 893, affirmed in part, vacated in part, and remanded) suggests that individuals seeking a “most integrated setting” for their long term care may well have strong claims to home-based care, and perhaps even consumer-directed care. While *Olmstead* concentrated on distinctions between institutional and community care, the same reasoning that prevailed there would also seem to apply when comparing different forms of community based care.

This brief discussion is intended only to demonstrate the fluid nature in the evolution of community-based long term care for the elderly. For reasons which are not entirely clear, the “organized elderly”, to the extent that such a group exists in fact, have not pushed community based consumer directed long term care to a priority position in its policy agenda(Simon-Rusinowitz and Hofland 1993). The elderly have concentrated on avoidance of nursing home placement and remaining at home as long as possible as primary goals. The independent living movement and the developmental disability movement have emphasized full participation in the larger community, independence, control of services, and choice.

## **Demonstrations, Evaluations, and Past Experience**

While all states provide for some degree of community based home care services for the elderly disabled eligible for the state's Medicaid program, fewer than half report consumer directed programs.(Ladd 1998, Flanagan and Green 1997, Scala and Mayberry 1977).

State LTC Profiles Report, 1996. National assessment of state programs is, at this point, heavily oriented toward very broad considerations of allocation of resources to institutional vs. non-institutional programs, demand on the public long term care system, nursing home utilization and cost, and commitment to home and community based utilization and expenditure(Ladd 1999). While important for developing national policy and federal legislation, these assessments are less useful for individual jurisdictions. Since they rely almost entirely on expenditure summaries, case counts, and gross population by age counts, they cannot take into account vital factors such as recent and distant state history, tax structures, revenues, relative wealth, population density, migration patterns and other demographic considerations, economic infrastructure, or issues of consumer preferences, quality of services, or characteristics of programs offered.

Participants' Experiences in Five Countries. In 1999, AARP published results of a bibliographic review of participants' experiences in consumer-directed long-term care programs in Germany, Austria, the Netherlands, France and the U. S.(Tilly and Bectel 1999). Even after accounting for differences in context and methodology, this review concluded that persons managing their own long term care services experienced greater choice and control than those using agency controlled services. A second consistent

finding was that participants did not perceive any diminution in quality of service under consumer-directed models. In the Netherlands and California, participants noted improvements in well-being. Finally, in the Netherlands and California, participants in consumer-directed programs reported *increases* in numbers of hours of service.

The report also suggested a number of caveats: (1) Not everyone prefers consumer directed models. Some do not want either the responsibility or the burdens associated with consumer direction. Indeed, in the Netherlands, more than half of those offered the opportunity to participate in the demonstration program declined. (2) Support by an informal network was an important component, suggesting that support for family, in particular compensation for family caregivers deserves attention. (3) Providing options to hire, train, supervise, and dismiss assistants while others carry out administrative and fiscal tasks may be an important option. In general, the survey suggested that maintaining a wide range of options may be the best way to facilitate consumer control.

### **Comparison of Client-Directed and Professional Management Models – California.**

One of the most relevant studies of Consumer-Directed and Agency Directed in-home programs to the New York City Alzheimer's Association Demonstration Project is a comparison of the two models of service in California. This study was conducted under the auspice of the Office of the Assistant Secretary for Planning and Education (ASPE) and the Office of Disability, Aging and Long Term Care Policy (DALTCP) of the U. S. Department of Health and Human Services (DHHS) (Doty et al 1999). The study was based on 1996 data.

California and New York rank among the highest of the states in the percentage of Medicaid Home and Community Based Services Cases compared to total Medicaid Long Term Care Cases(Ladd 1999) with New York at 87.6 %, and California at 76.9 %. The range for the entire country according to the University of Minnesota study is from the New York high to a low of 4.4% for Pennsylvania.

Only a handful of states presented the possibility of a formal study comparing a consumer directed model (CDM) with a professional management model (PMM), often referred to as an agency directed model. California's In-home Supportive Services (IHSS) Program furnishes services to 200,000 individuals, with the CDM available in 58 counties and PMM available in only 12 counties. Over 90 % of clients received services through the CDM. This finding alone suggests the importance of exploring in considerable detail the contrary experience within the New York City program.

The New York City Demonstration described in detail below was designed to determine the utility of a supportive intermediary for individuals and families seeking participation in the consumer directed personal assistant program (CDPAP) for individuals with a dementing illness. The report of the California Study touches on special aspects of the CDM and PMM approaches which deserve special attention in New York and elsewhere.

The findings of the study covered client and provider characteristics in both models and within the CDM where clients hired family members compared to others, client experiences, provider characteristics, training, benefits and working conditions, client outcomes and worker outcomes.

The study's conclusions are important for the further examination of the program in New York City. At minimum they offer the basis for hypothesis building as both the basic CDPAP program for persons with dementia and the supportive intermediary program of the Alzheimer's Association are evaluated and assessed.

At the risk of considerable oversimplification the California study concluded the following:

- Both models (i.e. CDM and PMM) have clearly demonstrable positive outcomes for large majorities of both clients and workers.
- The consumer model yielded superior results on several measurement dimensions related to client satisfaction with services, empowerment and quality of life.
- The fixed monthly cap on IHSS expenditures for clients *does* limit the ability of the program to meet the needs of some highly disabled clients.
- Contrary to the conventional wisdom, the PMM was *not* found to have better outcomes with respect to client safety.
- Approximately one quarter of CDM clients experienced difficulties in recruiting a provider, a difficulty not experienced by PMM providers. However, in both models one third reported concern about securing back-up assistance.
- While it was difficult to conclude either favorable or unfavorable client outcomes where supportive services were available, the study commented that “. . . it was apparent that some CDM clients could benefit from more assistance in meeting the challenges of consumer direction-especially those involving provider recruitment and ensuring access to backup workers.”
- Clients who hire family members as their providers do have, on average, better outcomes than those who hire non-family members, with significantly better outcomes on some dimensions of safety, satisfaction with services and empowerment among CDSM clients.
- Much of the sense of security and satisfaction with the CDM, accounting for 90 % of the participants, appears to be highly associated with the ability to hire family members as the provider.
- Concerns about agency liability under the California Nurse Practice Act appears to restrict medically oriented services provided under the PMM.

- While worker satisfaction appears high in both models, agency employed workers earned about 30 % more than client directed workers.
- Despite the pay differential, the CDM offers greater programmatic cost efficiencies. Thus, even if pay rates were the same, CDM costs would still be lower because of the PMM's higher administrative overhead.

Clearly, this study has implications for examining the New York City program.

These include issues concerning the choice between the consumer directed vs. the agency directed model and the special considerations involved in CDPAP for people with dementing illnesses.

A final issue for the New York City demonstration is the contribution, if any, of the supportive intermediary and the other supportive services available from the Alzheimer's Association.

### **Demonstrations Underway – Cash and Counseling, and Independent Choices**

Currently underway are two sets of demonstrations involving issues in consumer direction: The Cash and Counseling Demonstration and Evaluation funded jointly by the Robert Wood Johnson Foundation and the USDHHS (Doty 1998), and the Independent Choices program of which the New York City program discussed below is a part. Independent Choices is funded by the Robert Wood Johnson program.

The Cash and Counseling program was initially slated to take place in four states: Arkansas, New York, Florida, and New Jersey. While high levels of interest in consumer direction were found among consumers themselves and among family members in all four states, New York State dropped out because it was unable to meet all conditions specified in the demonstration protocol in New York City. However, prior to withdrawing from the demonstration, preliminary qualitative inquiry did take place in New York City.

Five focus groups with a total of 36 participants were conducted in New York---two in Westchester County, a New York City suburban area, and three within the City itself. Members of the groups were drawn from lists provided by agencies providing personal care services for people with disabilities. The focus groups centered on consumer satisfaction with services being received, reactions to the proposed cash and counseling program, and a comparison between and among certain groups about the current program (i.e. the agency directed program) and the Cash and Counseling program (Zacharias 1997). The qualitative material obtained through these focus groups was then used in fashioning a broader quantitative telephone survey.

Following the telephone survey conducted in New York from April to June, 1997, three focus groups were convened in New York City---two consumer groups divided along racial lines, and one group of Caucasian surrogates (Zacharias 1998). The post survey focus groups had three primary goals: (1) to explore the concept of Cash and Counseling by consumers and/or surrogates, (2) to explore key findings from the telephone survey, and (3) to test material to market the Cash and Counseling program.

The reports from both sets while useful in examining understandings, perceptions, and preferences of persons receiving services under an agency model, i.e. prospective to the cash and counseling demonstration, must be approached cautiously. The focus groups were overwhelmingly female: 28 of 36 participants in the first round, and 12 of 16 in the second round. None of the focus group members were involved with dementia. All focus group members were required to have a good working knowledge of English which excluded what might be a key group for consumer-directed care (non-English-

speaking elderly persons or their surrogates), and one focus group in the second round had only two members.

In general, there was support for the concept of cash and counseling. Findings from the focus group were somewhat equivocal, the most positive aspect for surrogates being that it was a way of keeping their elderly relatives out of a nursing home. For participants, it was having a voice in who would take care of them.

There were differences between older and younger participants (older participants expressing greater satisfaction with their agency program than younger participants), and between Caucasian and African-American participants (the latter seemingly more interested in the Cash and Counseling program than Caucasians).

These differences suggest the need for even deeper qualitative inquiry. Some aspects received that attention in the study described below.

### **Qualitative Issues in Consumer Directed Personal Assistant Services for Persons with Cognitive Disabilities – New York City**

The Historical Roots of the Supportive Intermediary Project. The Supportive Intermediary Project has its roots in the substantial history and trends of social and health programs of the second half of the twentieth century. This history includes the development of health care services for the poor and medically indigent, the Independent Living Movement, the closing and depopulation of institutions for the mentally ill and mentally retarded, and the rise of the nursing home as America's new mental institution.

One might say that

- The steep growth in the number of long term care facilities and their emergence as the primary locus of long term care service for the elderly.
- The emergence of federal reimbursement for health services for the poor and medically indigent under Title XIX (Medicaid) of the Social Security Act beginning in 1965.

- The depopulation of America's State Mental Hospitals followed by closings of State Schools for people with mental retardation. This change resulted from the development of: a) the psychotropic drugs, b) the concomitant substantial Community Mental Health Movement, and a little later, c) the significant court cases holding that large state institutions for people with developmental disabilities were counter to their interests and d) the development of community services for people with mental retardation; and finally,
- the emergence of the Independent Living Movement energetically trumpeting consumer directed community based services, first for severely involved physically disabled persons, and subsequently for developmentally disabled persons.

The supportive intermediary project for persons with dementia grows out of social policy history, and is a logical extension of what has gone before. In New York City, at least, the Supportive Intermediary is an innovation in a program which heretofore had served only persons with physical disabilities with the capacity to direct their own care.

A consumer directed services program for people with cognitive disabilities is more complex than the predecessor programs. Its complexity is parallel to that presented in the consumer direction programs for persons with developmental disabilities (namely, self-determination) in its reliance on surrogate decision-makers who act and decide on behalf of the person with disabilities.

## **METHODOLOGY**

### **Organizational Framework**

The Medicaid-funded Consumer Directed Personal Assistance Program (CDPAP) in New York State/New York City is based on the belief that consumer empowerment through control, choice, and flexibility in care plan decision making is appropriate and cost effective for persons with disabilities or chronic illnesses. CDPAP enables the

consumer to recruit, hire, train, and dismiss the home care worker employed and to schedule tasks and use of personal care hours.

The project of the Alzheimer's Association, New York City Chapter is focussed on facilitating and effectuating consumer-directed care for the cognitively impaired, with family members or other designated adults acting on their behalf.

Specifically, the project seeks to define, test, and implement the role of a supportive intermediary in helping the family/designated caregiver manage the care of the cognitively impaired consumer. Over the three year Robert Wood Johnson (RWJ) grant period, the NYC project staff seeks to define the counseling needs of families/designated caregivers and to determine the extent to which a supportive intermediary service is, or is not, needed, and the extent to which it improves the ability of cognitively impaired elderly and their surrogates to access and utilize the CDPAP option.

As an integral component of offering counseling and chapter support services to families in accessing and managing consumer-directed care, the project involves collaboration with two separate agencies. The first, Concepts of Independence (Concepts) runs the consumer-directed home care agency for persons eligible for CDPAP/Medicaid home care services in New York City. The role of Concepts is to serve as the fiscal intermediary and as the employer of record for the home care workers. The second collaborative agency is the New York City Human Resource Administration (HRA), the regulatory agency responsible for Medicaid eligibility and home care services.

The Center for Outcome Analysis (COA) was retained to evaluate, from a consumer/family point of view, the role of the supportive intermediary. (COA withdrew from its role as the independent evaluator after completing the first year evaluation.)

The qualitative analysis focussed on sixteen participants who were studied for one year. This study describes what occurred, what information was gathered and what obstacles were encountered. Although the sample was small and limited to the first year time span, the personal impressions and concerns expressed provided valuable insight on a new supportive service.

This is a preliminary project analysis and its conclusions are tentative. At this point, we believe the supportive intermediary position is an important component of self directed care for certain people with cognitive disabilities. Additionally, we conclude that further research that includes the study of a larger sample of participants and that tracks outcomes over the years of project participation is warranted.

The methods and scope of the evaluation of the Consumer-Directed Personal Assistance Program for Persons with Cognitive Impairments was dictated by the objectives, methods, and anticipated outcomes of the original grant proposal to the Robert Wood Johnson Foundation. The evaluation was also guided by the philosophical basis of the project, namely a belief in the value of consumer choice, consumer direction, and consumer autonomy as set out above.

The original plan for analysis was to utilize both qualitative and quantitative research methods. The plan of action was to collect simultaneously both types of data, triangulate the information to develop a description of the Supportive Intermediary pilot project, and finally to evaluate its impact. However, early on, it became clear that the

initial stage of evaluation needed to focus on purely qualitative analysis. This modification was mainly due to the small number of participants enrolled in the project at that time, the lack of any significant data relative to preferences of surrogates, perceptions of program quality, and the lack of information about surrogates views or activities. In addition, we concluded the following:

1. A predetermined set of survey questions was not consistent with the exploratory nature of the program.

A major goal of the first program year was to determine the needs of the participants. The initial phase of the evaluation therefore required a less structured approach: one that would elicit people's perceptions and develop constructs around the use of the Supportive Intermediary Program.

A stated major "Planned Accomplishment" of the project was to demonstrate that

The consumer-based, intermediary-supported model will lead to enhanced quality of life and satisfaction for both the consumer and the family or designated caregivers.

The measurement of enhanced quality of life and satisfaction requires comparative data of the independent variables (i.e. consumer-directed and supportive intermediary interventions). This data was not readily available.

2. The numbers of consumer/surrogates was too small to enable statistical generalization. Further, the sample population was heterogeneous, including individuals in various stages of dementing diseases, in a variety of living circumstances, and with caregivers whose capacities, knowledge and abilities

varied widely. The characteristics of this sample population are ideal for qualitative methods as we were able to interview virtually 100 % of enrolled participants and develop an understanding of the unique complexities facing the participants and surrogates.

There is little question that most people want more control over the services they receive. Unfortunately, regulatory constraints often limit consumer flexibility and accommodation, particularly in home care service paradigms.

Above all, social policies seek to rationalize and regulate an activity that is ultimately unmanageable. Although some policymakers take as their starting point the needs of caregivers, many others seek to manipulate family members in pursuit of economic efficiency...Because the services caregivers provide are embedded in intense personal relationships, most aspects of their endeavors defy state regulation and economic control. (Abel at. 62).

Nursing homes and congregate living situations are the usual settings for most of the literature on people with Alzheimer's and other dementia, necessitating evaluators to explore social environments and community formation (McAllister & Silverman 1999). Indeed, when people are removed from their homes and separated from loved ones such foci are necessary. However, this project begins with a focus on the maintenance of community and the choices associated with that value. It is not surprising that many people prefer this arrangement and its inherent benefits. For example, studies of persons with cognitive and other developmental disabilities have shown that consumer directed services are very successful, increase quality of life, and save taxpayer dollars (Conroy & Yuskas 1996 ). Thus, the central question of this evaluation was *not* whether consumer directed services can work for some people with cognitive

disabilities. Rather, it was focussed on the role of a supportive intermediary in facilitating consumer directed care for people with dementia and with family or other designated caregivers acting on their behalf.

### **The Qualitative Methodology**

Qualitative methods have long been used to understand social phenomena, having roots that extend into social psychology, anthropology, and sociology. Simply speaking, qualitative inquiry is a systematic approach that, depending on the adopted school of thought, examines culture, social interaction, constructed categories of meaning, and/or linguistics in a natural setting. The data collection method generally uses a combination consisting of open-ended interviews, document analysis, and participant observation, (Bogdan & Biklen 1998; Lincoln, 1985; Guba & Lincoln, 1989 ).

Qualitative inquiry has a long history of application in program evaluation (Patton, 1987, 1982). It can be designed to look at individual cases or groups. But in either situation, it is likely to emphasize personal contact with the study participants (Bogdan & Biklen 1998 , Marshall & Rossman 1989, Patton, 1987, 1982). As such, the qualitative approach provides explanations, descriptions and stories directly from project participants. It is therefore helpful to use qualitative inquiry in program evaluations that are exploratory in nature or have constructs that are difficult to define.

While the qualitative approach is interpretive and exploratory, the quantitative approach is standardized, results in levels and quantities, and is predictive (Dill et al., 1995 at 9). When using the two methods together

(methodological triangulation), researchers and evaluators generally use one to enhance the performance of the other. In this case, qualitative inquiry is applied prior to survey methodology. In this way it can help to develop accurate survey questions and generate sound hypotheses. The exploratory nature of the qualitative approach assures that important topics are covered in subsequent surveys and in an appropriate fashion. (See Morgan, 1998 for a discussion about combining methodologies).

This report summarizes the findings of the first year qualitative evaluation of the Supportive Intermediary Program.

### **Description of Year One Evaluation Process**

The goals of the qualitative evaluation were to:

- better explain both the premises of consumer-directed care for persons with Alzheimer's disease and dementia, and the Supportive Intermediary interventions, based on actual application,
- understand the use of language and its meaning in regard to the Supportive Intermediary and the consumer-directed program to surrogates to public agency officials, and to the fiscal intermediary, Concepts, Inc.,
- identify potential problems and barriers encountered in the CDPAP and strategies to overcome them, and
- generate ideas that can be tested using quantitative methods.

Preliminary work included a review of literature and documents, a focus group and several individual interviews that yielded general topics of interest. The topics, in turn, were summarized as an open-ended, exploratory interview

protocol used in the interviews (McCracken, 1988), particularly related to the consumer directed program in New York State. While the interview guide was intended as a tool for individual interviews, considerable time was allotted to probe and explore topics raised by participants that may not have been included in the outline.

The study participants were selected by a purposeful sampling technique (Bogdan & Biklen 1998; Patton 1987). A total of twenty people participated in the individual interviews. All participants in the consumer-directed program were contacted and asked if they would consent to be interviewed, including those who had not been involved in the Supportive Intermediary Project. Three individuals declined. One person was contacted but was not interviewed because it was not possible to overcome a severe language barrier. Sixteen of the interviewees were surrogates involved in the consumer directed program (thirteen of those were involved in the Supportive Intermediary Program and three were people who had enrolled directly in the consumer-directed program without contact with the Supportive Intermediary). The other four interviewees were professional staff from The Alzheimer's Association - New York City Chapter, Concepts of Independence, Inc., and the Bureau of Professional and Medical Review, Home Care Services Program of the New York City Human Resources Administration.

The collected data consisted of field notes, personal observations, and interview transcripts, combined with reports and manuscripts collected from the Project. This information plus research on pertinent topics constituted the entirety of the data analyzed.

### **Data Analysis**

The interviews were conducted by an analyst and report co-author from the Center for Outcome Analysis. He visited sixteen of the people involved in the project. All interviews were recorded and transcribed. Participants were assured that their responses were confidential and that their identity would not be revealed.

All of the information was inductively analyzed to develop an understanding of concepts that are difficult to describe or define (see Bogdan & Biklen, 1998 for a detailed description of inductive analytic techniques). That is, transcript data were repeatedly read and labeled according to common themes found throughout the data. The themes extracted from the data served as the basis for constructing this report. The key themes extracted from the data are as follows:

- perceptions and definitions of consumer directed personal care,
- the role of the supportive intermediary,
- the role of interfacing agencies, and
- utilization of the program.

### **Participants**

Fourteen of the sixteen consumers in this study had a primary diagnosis of Alzheimer's disease; one had a primary diagnosis of severe dementia, and the other, progressive supranuclear palsy. Their ages ranged from 62 to 92, with a median age of 82.5 years. Ten of the sixteen had daughters as their primary surrogate. Other surrogates included spouses, one son and one son-in-law. The median age of the primary surrogate was 55, with a range from 33 to 83 years.

Nine of the sixteen consumers had at least one additional surrogate assisting the primary, while three had two additional surrogates.

In all, the number of unpaid hours of assistance totaled 831 weekly, with an average of 52 hours contributed weekly by unpaid surrogates or other unpaid supporters. This is compared to Medicaid funded weekly hours totaling 1104, or an average of 106 weekly hours of allotted paid personal attendant care. In other words, Medicaid is funding an average per person amount of 106 hours of personal attendant care weekly, while the surrogates involved in CDPAP are making personal contributions of half that number, or 52 hours weekly.

In summary, surrogates tend to be daughters with income described as moderate and who have made a major time commitment to care for their relative with dementia. They are contributing, either alone or in combination with at least one other surrogate, approximately 52 hours of care per week. Their commitment involves a significant amount of direct personal care and management/administrative activities related to the care of their relative.

## **Statement of Limitations**

Despite the fact that the entire population of people involved in the Association's Supportive Intermediary project were interviewed, the small number prevents any generalization to the entire population of people with dementia who may participate in CDPAP in the future. In other words, because qualitative research is composed of non-representative samples, the information collected should not be interpreted as reflective of the entire population (Krueger, 1989). Therefore the evaluation is not conducive to generalization or to a frequency count.

It is important to note that the choices in the Consumer-Directed Personal Assistance program are made by surrogates, rather than by first line consumers of the program. Therefore, it is important to keep in mind that responses in the interviews reflect the *perceptions of surrogates* about the benefits of the program for both their relative with dementia and for themselves as major purveyors of care. There is an assumption that the surrogate can speak with the consumer's best interests in mind. Thus, the information herein represents a range of experience of the surrogates only, and most of what is reported is perceptual in nature. Our assumption is that all perceptions and experiences collected in a qualitative inquiry are valid. However, because of the diversity in individual experiences, it is possible that the interview data may contain contradictions or perceptual inconsistencies.

This study must be understood within the limitations of the method used for collection and analysis. The information is intended to be descriptive, preliminary, and complimentary to any additional survey data that will be

collected throughout the demonstration period. These parameters should be kept in mind when interpreting the results.

## **KEY FINDINGS**

These findings represent important topics as identified by surrogates. Their perceptions were based on personal situations and in response to the program and their experiences with various collateral agencies.

### **The Journey to Consumer Directed Care: Reflections by Surrogates of Persons with Dementia**

The Role of the Surrogate. The primary caretaker or surrogate is the person presumed most able to connect the past to the present, respecting the life and contributions of the individual whom dementia has significantly changed. The surrogate is someone who can remember the preferences and individual qualities of the person prior to the onset of disease, information that plays a crucial part in defining their existence. Given that the surrogate is mainly responsible for maintaining both the historical identity and the quality of life for their relative, a first logical step in studying the CDPAP is to elicit the surrogates' perspectives and interpretations of the program. A large part of our information gathering, therefore, centered on the experiences of the surrogates, their interpretations of the service system, the meaning they assigned to their roles and the outside assistance they received through the CDPAP Program.

The diagnosis of a dementing illness is the beginning of a journey that involves considerable, if not continuous, change and adaptation in relationships and roles for surrogates and their relatives. It is clear that the role of the

surrogate is the most crucial element in the success of the CDPAP for persons with dementia.

The role of surrogate is often thrust upon persons who already have considerable life responsibilities such as children and careers. Often without time for planning or research into options or resources, they must find the time to devote many hours per week to this new and stressful task. Many report patterns of frequently utilizing sick days from work and developing a process for sharing care giving responsibilities with spouses, siblings and adult children. Assuming the role of surrogate significantly adds to the quantity of tasks that a person must address on a day to day basis:

*During the week I usually run by during the day on my lunch hour - it's about 15 minutes from where I work - and just make sure that she's okay and that the homemaker is doing all that is required. Then I come back again after work. I usually come and stay with her for about another hour and a half. I make sure that she has dinner and just talk with her and give her some kind of socialization. And once I get in, I call her again and that takes us to about 8 o'clock and then again at 9 o'clock I call her and make sure she goes and takes the medicine.*

Many surrogates described their role as all encompassing; as doing “everything” for their relative. Essentially, when paid Personal Assistants were not present, the surrogate assumed the responsibilities of caring for their relative with dementia. The caretaker role involved participation in all daily living activities such as, self-care, cooking, laundry, toileting, and communications with outsiders and managing finances.

*[I do] everything ... during the day, we have a personal assistant who does everything for her - feeds her, bathes her, takes her out, all her care. When she leaves, it's my responsibility to pick up where she left off, giving her a snack before putting her to bed, tucking her in, and just watching her.*

*I do everything that the personal assistants do. I have personal assistants for 12 hours a day and I am it for the other 12 hours. So whatever needs doing, I do. I take care of all of our affairs as far as business affairs – insurance, shopping, and communications. The aides leave at 8:00 PM and come back at 8:00 AM ... whatever care he needs in the meantime, I do.*

*Everything! I have to think for her, I have to take care of her business. She can't do anything.*

*I have to do the cooking. I have to do the laundry ... me ... I'm doing it for her. I have to watch how she eats. After the [personal attendants] go home, it's 8:00 o'clock. I take over until the next day. I have to turn her over at night 2-3 times, change her, and give her some juice or water, whatever. More or less, I'm up all the time.*

*So I have to do everything there is to do for my wife and she's almost incapable of doing anything.*

Other surrogates described their roles as administrators, managers and coaches. They perceived themselves as front line supervisors, managing their relatives' paid caretakers. The administrative role is directly related to having 24 hour a day personal attendant coverage. Families with 12 hours of coverage per day obviously provide more direct care for their relatives. It seems the difference between doing “everything” and managing others who do the direct care lies in the ability to access 24-hour care from Medicaid.

*I supervise the aides. I did the shopping. At one time I had the [personal attendant] only during the day and I took care of her at night. Later on I had the [personal assistant] for 24 hours. So that relieved me of it and I kept on doing the food shopping and whatever else she needed.*

*I take care of all of our affairs as far as business affairs - insurance, shopping, and communications.*

*I take care of all the paper work with regard to administering the Consumer Directed Program - all the paper work, all the communications*

*with Concepts, with CASA, which is a Medicaid provider, any paper work. My father can't do it.*

*I coordinate her appointments with the various doctors. I coordinate the personal assistant schedules. I do nutrition menu for her so [personal assistants] can follow. I interface with all the bureaucratic people such as Medicaid, Medicare, and Concepts, everything. I also do all her financial stuff, make sure the rent gets paid, make sure there's food in the house, everything that is needed.*

*I shop for her, food shop and manage her finances. I kind of make sure that everything she needs to have done is done.*

*I give her medication... I manage her financial affairs. I supervise the caregiver over there. And I think I offer her some kind of moral support.*

*I am the "manager" of the personal care system . . . I do all the shopping. I do the laundry. I actually do some physical therapy, so every day she gets a good range of motion and exercises. And I train the home the attendants, personal care assistants, to do this. I'm involved with all medical things for my mother, so I take her to physicians; I go to the dermatologist with her. ...I define [the job responsibilities] and I just tell [the personal assistant] this is what has to be done. If there are any medical things, like the physical therapy range of motion, I show [the personal assistant] how to do these things and tell her what to do if there's medication that have to be given. I clearly write out when the medication has to be given - if with a glass of water, on an empty stomach.*

In summary, the demands and expectations on the surrogate involved in consumer directed home care are considerable. Indicators of that role involve five general activities:

1. Assisting with activities of daily living, including feeding, bathing, dressing, shopping, laundry and a host of other activities involved in day to day care of the person.
2. Personnel management, including defining the needs of their relative and the job responsibilities for the personal assistant, planning and coordinating schedules, hiring, training, supervising, and dismissing staff, when necessary.

3. Business and financial management, including coordination and payment of household bills and insurance policies, acting as liaison with involved agencies, completing paperwork, handling investments, divestiture, and legal activities, etc.
4. Medical and therapeutic interventions, including medication administration, handling doctor appointments, planning and coordinating dietary needs and nutritionally sound meals, positioning, and implementing physical and other in-home therapies.
5. Socialization including making plans and arrangements for pleasurable activities and opportunities for family and community interaction.

The commitment to each of these responsibilities varies in relation to the allotted hours of paid personal assistance. The addition of paid care hours usually resulted in a shift towards more managerial tasks for the surrogate not an actual decrease in actual hours devoted to the care of their relatives.

The majority of surrogates interviewed were fortunate to have management skills that enabled them to take on their new role. Many presented as well educated and financially secure. Nine of the seventeen respondents were clearly engaged in professional and/or executive level employment, three were engaged in middle management/ supervisory level employment, and five either had no work experience or worked at semi-skilled or unskilled labor either currently or prior to retirement.

Progression of the Disease. The progress of dementia is often slow and fluctuating and always challenging for people with the disease and those closest to

them. In this study, the most frequent experience encountered by surrogates was their relatives' loss of short-term memory.

*She started forgetting things...she didn't want to be alone.*

*Her short-term memory was lousy. She couldn't remember anything. She could tell you about when she was five and when she was six like it happened yesterday, but short term was gone.*

*She very rarely could remember who called. I would ask her to write it down, and she said she would, and then she wouldn't. I would ask her how come, and she said she forgot. Two and a half years ago, she was much more aware of things and could, to answer your question more directly, she could, to some degree, direct me or the personal assistant. Today, she cannot.*

Surrogates reported another major milestone in the progress of dementia as the point when their relative could no longer be left alone. This dependency resulted in an increased level of involvement for the surrogates. In fact, a logical conclusion is that the role of the surrogate becomes clearly defined at this critical point in the progression of the disease

*I thought I could leave him alone in the morning. Well, I'd come back and he wouldn't be there. Things like that. So he did have Alzheimer's. It evidenced itself at that time, that he couldn't really remember how to get back to [his home].*

*I know my mother was a very independent, a very dominating figure. All of a sudden, she started getting real dependent. She kept wanting people to go with her on appointments and stuff like tha*

Another reported characteristic of the progression of dementia was personality change. Behaviors typically associated with mental illness, such as aggression, mania, paranoia, and hoarding required additional adaptation in the changing relationship.

*She started in 1989. She went through the usual aggressive behaviors of the Alzheimer's disease. At one point she was aggressive. At one point she was wandering. She had the usual progressive situation . . .*

*She started to hide clothing around the house. My parents have a house up state. My father would find clothing hidden in trees outside.*

*In 1985 she started with the Parkinson's. But Alzheimer's was first - the forgetting and all that anger and nervous reaction, walking around like crazy. She wouldn't sit down for a second. She used to come up and down; down [to the basement] like 50 to 60 times a day.*

*Paranoia, I'll say schizophrenia, where she would watch television and [perceive that] the person is out to get her.*

Some surrogates experienced the total transformation of their relative.

This stage was often marked by the person's inability to communicate and represented a loss of identity.

*In the early stages of the disease, my mother was able to express her preferences and desires and, of course, we acknowledged them. But as the disease progressed, her capability to express these things diminished.*

Most families initially sought help when the person with dementia showed signs of deteriorating mental capacity. There were two primary sets of circumstances that prompted the surrogates interviewed to accept new responsibilities and to seek outside help. The first was increased incidents of wandering and the second was the inability of the primary caregiver to safely handle behavior incidents. The danger associated with these situations led to a realization of the need for assistance.

*At a point when my wife wandered on the street looking for me and the neighbor picked her up and at that point my daughters suggested that we need some help.*

*I think I originally got in touch with them because he had walked out one day and forgot how to get back.*

*She did wander. That's why I said my mother needs 24-hour care; because she also did it at night.*

As caregiving needs became more intense, the surrogates reevaluated their own capacity to deal with the situation. Below are several descriptions of this process:

*It was obvious that he was not getting adequate care with his wife.*

*She really deteriorated ... I couldn't handle her by myself anymore.*

*I got to the point where my illness was getting worse and I could not leave her alone and that's when I insisted that I need some kind of home care.*

*I needed to get some personal help for myself.*

*It was mostly information, but it was also partly in that I needed more help.*

*My mom was in Florida; I needed somebody to help me manage this.*

The road to consumer directed personal care is long and arduous for surrogates and their relatives, involving months and sometimes years of challenges and change. The caregiver's role begins with the deterioration of short-term memory and self-identity in the person with the disease. As dependency increases the surrogates seek help, especially when safety becomes an issue

### **New York City Medicaid Home Care Services**

The search for help most often began with the Medicaid Program. In particular, the people in this study were led to the Medicaid Home Care Services Program. Home care/personal care services in New York City are typically carried out by home care vendor agencies that provide home attendants/personal care workers to persons eligible for Medicaid and home care. Consumer-directed care is also available, although it is little used---less than 3 % of the home based care in New York City is consumer directed.

Concepts is the sole consumer-directed vendor agency in New York City. Consumer- directed care for cognitively impaired persons not in the mental retardation programs is a recent development. Most recipients of home-based care receive their service from traditional agency-directed service providers.

Medicaid in-home personal care services are an integral part of New York State's Medicaid program. That is to say, the home care services program is not one authorized under federal Medicaid waiver provisions. The availability of personal care service hours varies from county to county with New York City using the bulk of Medicaid home care dollars and hours of personal care.

In the initial interview for home care services, state policy requires that the consumer-directed personal assistance program option (CDPAP) be presented. However, personnel at both HRA (the New York City regulatory agency for Medicaid and home care) and the family designated caregivers interviewed indicated that information about CDPAP and enrollment in Concepts is often not offered.

*The city did nothing to encourage it, in general. And while it was publicized within the community, we would have to talk more specifically to people with disabilities, ... a lot of people were simply never told ... in the CASA or HRA ...they just never told anybody ... so people went to traditional home care.*

*Doctors don't even know about the home care program.*

*I don't believe that many people know about it...In my opinion, I belong to that support group [at the Alzheimer's Association] and I have told them many times about Concepts and nobody knew it. I think it's a well-kept secret! Basically, I think nobody knows about it. It's not publicized.*

*I think people don't know about it [consumer directed care].*

*The issue, I guess, is how well the Concepts Program is publicized. I was not aware of it in any form until that meeting at Down State Medical.*

Surrogates who were not satisfied with services provided by the traditional service system, i.e. the agency-directed home care service, then approached the CDPAP. In many ways, their dissatisfaction with traditional services prompted them to seek the consumer-directed alternative. Surrogates cited inflexible schedules and staff issues, specifically the inability to hire supervise and fire home attendants, as the major reasons they chose to participate in the consumer directed option.

*Well, it (agency provided service) worked out very well with the exception, of course, that not all the home care workers that you get are the ones you want, or you have to change them or complications come up.*

*I never knew from day to day who would show up ... the quality of the people [home attendants] I got was very, very poor ... we had all of the issues of feelings of powerlessness and wanting to please them [personal assistants] ... trying to figure out how much I could assert myself ... that whole story ... all of those issues ... I was very, very unhappy.*

*I would like to know who is taking care of my mom. I want to have the say so on her care, not a stranger that does not know her or sits with her for five or ten minutes and tells me what's best for my mom.*

*One of the reasons why I really ran to Concept was because the old home health attendant loved my mom and she got a little too close I think, but she treated her very child-like. She talked to her like she was a child. When they crossed the street, she'd hold her hand. And like, "oh, mommy", "no, you have to do this" - like a child and it was eating at me and I spoke with her about it I don't know how many times and nothing changed, so I was so glad to find Concepts.*

*With the other program the way they set it up, I couldn't speak to her [the home attendant] directly if there were any problems. I had to speak to the nurse who wasn't always there and she would speak to the home health attendant*

*I just didn't want to leave it to someone else where I would have no say so in it. ... if I could do something better ... I was willing to undertake the supervisory role...*

*the other people that they [the agency] sent, it was just one horror after another*

*I went from people that I had selected that I thought were excellent to the people that Medicaid were sending and it was an incredible ... the difference was night and day.*

Despite the seeming complexity of the application process for Medicaid and CDPAP, and contrary to conventional wisdom, it was perceived by most surrogates to have progressed smoothly. Information on the average time from Medicaid application to service reveals a range of two to twenty eight weeks. Respondents did not feel that time frames or process were a deterrent gaining more control of services. Following is a summary of surrogates' perceptions of the application process. The word “smoothly” was used repeatedly in their descriptions.

*We did the paper work and everything went smoothly.*

*It went smoothly.*

*Enrollment appeared to proceed without considerable difficulty. The paperwork was handled relatively smoothly.*

*Yes, that went smoothly ... a couple weeks.*

*I don't remember the procedure being a problem.*

*A lot smoother than I thought!*

*Everything went smoothly.*

*It took a little while as I recall, but it proceeded smoothly.*

*It went pretty smoothly but it was a little confusing. I was never sure ... it was very hard to figure out what should happen next or the time line, it was just very vague, I remember that. So, I was filling out papers and sending them in but they didn't seem that clear on, it just seemed confusing.*

On a more detailed note, surrogates described other application-related experiences, such as attending to the details involved in divestiture of assets to meet standards for financial eligibility:

*With the help of the Elder Lawyer, we made up the documents ... living wills, etc., we made some arrangements and some transfers so that he would be able to qualify for Medicaid ...*

and developing a plan of care:

*I called up and they sent me some paper work, then I wrote my "thesis" on how I was going to deal with my mother's problem - how I was going to take care of her, what was going to happen if this person took a day off...*

The few difficulties reported by respondents with regard to the application process generally involved a lack of information:

*I am not sure that I have been accepted in the Concepts program because of several things that happened to cause delays.*

*It went pretty smoothly but it was a little confusing. I was never sure ... it was very hard to figure out what should happen next or the time line, it was just very vague, I remember that. So, I was filling out papers and sending them in but they didn't seem that clear on, it just seemed confusing.*

The New York Medicaid application process is perceived by CDPAP surrogate participants to be satisfactory and not particularly burdensome. The time frame for procuring services also appears to be satisfactory. The program was only perceived as confusing when adequate information was not initially presented. However, surrogates felt that program information was acquired more by chance than by any concerted outreach program.

### **The Fiscal Intermediary for Consumer Directed Home Care: The Concepts Program**

Once people successfully navigate the Medicaid process and apply for the CDPAP, the next step is to become familiar with the paperwork associated with managing and hiring staff. Assistance in this area is provided by Concepts for Independence, Inc., as the home care agency serving as the fiscal intermediary organization.

Concepts was founded by a group of self-advocates with physical disabilities who wanted to exercise more control in their lives and to participate fully as members of their communities. Specifically, they wanted to select and supervise their personal assistants, whether paid for by public or private resources. The organization created a service delivery structure that vested power and decision making in consumers rather than agencies.

*We [Concepts] had independently begun to put together the idea of a fiscal conduit, sort of like a pension system in which they [the State] receives a document requesting payment and we will then in turn submit the payment to the consumer. So that idea goes back. It was built into our articles of incorporation and became Concepts. [But] we had to sit on that idea for about three years from the time we became incorporated. It was a long process of negotiation with members of the disabled community and the City.*

Concepts incorporated and received its first contract to provide fiscal services for persons directing their own home care, through Medicaid Home Care in 1980. The program began modestly with four consumers. It provided the mechanisms whereby an individual with a disability, eligible for Medicaid and personal care, could manage their own home care attendant. (In keeping with the idea that task assignment could be different, the home attendant began to be called the personal assistant.) Concepts is an integral part of the New York City Medicaid home care service.

### **Concepts--Embodiment of Consumer-direction**

An important development in the evolution of the consumer directed services was a waiver to the Nurse Practice Act. The waiver permitted home health aides to provide services that previously could only be delivered by registered or licensed practical nurses. The Nurse Practice Act waiver assured that professional oversight continue by requiring initial review and certification of need by qualified nurses, providing for training of home care attendants, and requiring careful review of the plan to assure quality care for the consumer.

The waiver to permit high level home care to be undertaken by paraprofessionals, home health aides or other personal care attendants was based on the reality that families had in fact been providing such care, e.g. catheter care, tube feedings, injections and similar services for years. It seemed reasonable to assume that non-professionals could learn the technical procedures that family members without professional training had acquired. Concepts identified the subsequent shift from professional to paraprofessional home care workers as the means to achieving considerable cost savings. As the state program developed and began to include people with cognitive disabilities, it expanded the definition of self-direction to include surrogates.

A significant number of Concepts' 1000 clients, 25%, utilize surrogates in implementing self-direction. These clients include children, people with dementia, or people with disabilities who choose not to take on these responsibilities. However, from the perspective of the total number of persons receiving home attendant services (50,000 annually) the number is small. It is not unreasonable to believe that the potential for more surrogate participants in CDPAP is great, given the eligible population of persons

with both physical and cognitive disabilities. It is this extension of CDPAP to people with cognitive disabilities that mainly concerns the Supportive Intermediary project.

Service Provided by Concepts. Concepts provides payroll and benefits management for consumers and/or their surrogates who have elected to recruit, hire, train and supervise their own personal assistants. Concepts relieves consumers/surrogates of all record keeping and tax reporting requirements associated with employment.

Concepts' legal status as employer of record is equally important as it allows the organization to offer CDPAP personal assistants a full array of benefits. For example, Concepts offers a broad range of health insurance benefits that include health, dental, vision, prescription drugs, life insurance, and pension plans. These fringe benefits are in addition to the required Social Security contributions, Unemployment and Worker's Compensation Insurance.

Concepts provides additional support by providing a framework for consumer and surrogate directed care within the benefit and eligibility structure of Medicaid funded Home Care. That framework identifies the respective roles of the surrogate, the consumer, the Department of Social Services personnel (HRA in NYC), the Personal Assistant, and Concepts staff. (Note: in 1999, the Department of Social Services in New York City merged with the Department of Health.) More importantly, it describes the responsibilities and obligations of all stakeholders that are necessary to achieve maximum benefits from the program. (Concepts 1998)

Concepts publishes a forty page consumer guide that details:

- program participation,

- program responsibilities,
- liability of the consumer/surrogate and Concepts respectively,
- issues of quality assurance,
- definitions and limitations of personal assistance,
- determinations of scope of the program,
- recruitment, qualifications, hiring, firing, retention of personal assistants,
- relationships with the Department of Social Services, and
- "How to do it" instruction on the nuts and bolts timekeeping, filings, and similar matters.

Most critical to the maintenance of quality and the prevention of abuse is the specification of surrogate qualifications, particularly in cases where the consumer is *not* self-directing. The Home Care Services Program of HRA has continuing reservations about the role of the surrogate, especially with respect to the surrogates' levels of involvement and physical proximity to the disabled person. There is real concern regarding the potential for exploitation and/or abuse.

In response to these concerns, Concepts, HRA, and the Alzheimer's Association together have created program policies to provide clear parameters for surrogate roles and duties. To qualify for the Concepts program the surrogate must:

- Reside with the Consumer; or
- Maintain a significant daily presence with the Consumer; or
- Visit the Consumer at home at least once a week and maintain a significant presence by establishing and insuring a system of coordinated daily visits to be completed either by the Surrogate or a designated adult backup; or

- Visit the Consumer at home at least once a week and be in receipt of support services from a social services agency with an approved plan on file at the local social services office (CASSA).

Furthermore, the surrogate must arrange for an effective back-up support system to insure continuity of service supervision.

It is important to note that Concepts is also very clear about its own role in the consumer/surrogate directed program. It does not offer counseling, mediation or intervention services for surrogates, consumers or home care workers. It provides payroll and benefit administrative services to Medicaid eligible persons who meet the Concepts qualifications for serving as a surrogate. Beyond that, it provides useful guidelines and advice for those electing self-directed care. It maintains and disseminates lists of agencies and organizations that employ qualified home care workers. It is clear that Concepts has played a major role in defining and pioneering parameters of consumer directed care for interested participants.

The surrogates interviewed did not make a clear distinction between the philosophy of consumer directed services and the program as administered by Concepts. As Concepts is the sole service organization currently offering CDPAP services, the two appear to be one and the same in the eyes of the surrogates. Their experiences with the Concepts/consumer directed program reflect their increased satisfaction as measured against their experience with traditional, agency-provided services. This satisfaction is largely a function of their feeling of control with respect to personnel decisions as well as perceived improvements in the quality of care for their relatives.

*Once I got with Concepts, I was able to interview people and hire and be able to set up policies and procedures and this is the way it was going to be done and if not, they [personal assistants] could go somewhere else ... so I have very good people.*

*Well, you're directing ... you're recruiting ... you're hiring ... you're training ... things you can really mold ... you can shape how things go ... also, you can make agreements so my people would not strand me if they're sick ... they'll still come in and they know that if they are sick, I wouldn't expect them to do anything except sit there with Allen just to make sure he was safe ... I'd also cut my day as short as possible and get back home ... it's a reciprocal relationship*

*It was my opportunity to find people that didn't have an established way ... they didn't have "their" established way of doing things ... they were open to what I wanted done for my mother ... for what my mother needed.*

*I think what really pleases me if now I'm able to talk to the home health attendant [re my needs and the needs of my mother].*

*And now I'm on Concepts, which I find a lot better because I have control over who exactly is going to be taking care of my mom. Everything that I have to say is positive for Concepts.*

*When I found Concepts, I couldn't believe that the fact that I could go back to that other person and have her paid through Medicaid was just wonderful... the few times that I have called to get a substitute from Concepts, through Concepts that's been very disappointing. Because of the quality of the people that they've sent.*

Another source of surrogate satisfaction with Concepts was the ability to participate in critical decision making with regard to their relatives' medical treatment.

*Concepts program allowed me to continue serving in this role, but it would also relieve me somewhat in the financial responsibility...there's a little administrative burden placed on the surrogate in terms of filling out the weekly pay sheets and so forth, but that's not really a problem...Concepts allows me to be actively involved and make what I consider critical decisions in terms of my mother's care... If there's a surrogate who doesn't want to be involved with the care of their loved one, Concepts is not for that person. In my case, I wanted to be involved. I wanted the best possible [services] for my mother and I felt that by my being involved, I could get the best.*

One surrogate expressed comfort in the fact that Concepts' bias for community based service allayed the fear of inevitable nursing home/ institutional service that is so dreaded by families dealing with Alzheimer's disease.

*It's a wonderful program to help people to stay in the community ...  
Compared to now, it was very bad and now I would say it's very good*

Another surrogate expressed a high level of satisfaction with the program's flexibility and responsiveness.

*This program is very satisfying. Every time I call and ask them a question there is always someone there to give me an answer and stuff like that. They are very flexible.*

One surrogate complained about her experience in hiring a Personal Assistant from the list provided by Concepts. (It is important to note that Concepts has no role in hiring Personal Assistants, it only provides surrogates with a list of qualified staff.)

*Concepts has worked out, but I must admit that I am not using it other than to access the funding. That part of it has been fabulous.... I have called to get a substitute through Concepts, that's been very disappointing ... Not the response. They don't send and they don't recommend, and I understand that. But that piece is not something that I would turn to again because it's been very disappointing whenever I've used those people.*

One surrogate reported that she was considering reverting to an agency directed arrangement. She felt the attendants did not pay attention to her direction, did not follow instructions, and were not carrying out specified tasks for her mother. She had previously been receiving satisfactory care through an agency but switched to CDPAP because of staff turnover rates. It should be noted that this particular individual expressed a dissonance between her needs and the inherent characteristics of the CDPAP. She did not find the added surrogate

responsibilities to her liking. We interpreted this as one situation where consumer directed care was clearly inappropriate to the needs of the individual and surrogate.

In New York, Concepts was the primary designer of the fiscal intermediary model. Many of the people who currently utilize the CDPAP rely on Concepts, as it is the sole fiscal intermediary organization in the city. Surrogates made no distinction between Concepts the organization and fiscal intermediary services in general. They perceived the agency and the methodology as one and the same.

Surrogates are generally satisfied with the services provided by Concepts. The organization's role and activities seem to be sufficient to meet most needs.

**The Supportive Intermediary: The Alzheimer's Association – NYC Chapter**

The New York City Chapter of the Alzheimer's Association has been funded by the Robert Wood Johnson Foundation to facilitate inclusion of people with Alzheimer's and dementia in CDPAP by defining and testing the supportive intermediary role.

Despite eligibility, large numbers of persons have not availed themselves of this service option. The Alzheimer's Association plans to identify the kinds of methods and supports needed by persons and their families to begin and follow through with consumer directed care. The challenge, as articulated by the organization, is to "define the extent to which a supportive intermediary is, or is not, necessary when non-self-directing persons with families/designated adults participate in consumer directed care models".

The qualitative study identified several supportive intermediary activities. These activities were judged to be important to the supportive intermediary role by surrogates and staff from involved agencies. They can be summarized as follows:

- Provide information and referral to surrogates interested in CDPAP;
- Provide short term counseling to surrogates experiencing crisis in coping with the demands of caring for their relatives;
- Coordinate peer group support to sustain surrogates in their caregiving role;
- Assist in the Medicaid, home care, and CDPAP application processes;
- Educate the community about the CDPAP option to home care;
- Provide material and technical assistance regarding staff recruiting, hiring and training.
- Provide educational seminars to surrogates addressing the many components of the CDPAP, including dementia related issues, personnel management, fiscal administration, etc.
- Address barriers that interfere with access and utilization of the CDPAP.
- Collaborate with Concepts and HRA to facilitate the administration of CDPAP for persons with dementia.

The Surrogates identified the roles of the Supportive Intermediary as providing education, information and referral, support and guidance, and help in accessing Medicaid.

*They started me off originally when I asked them, they got me all the information I needed and they put me in touch with the activities for my wife and, of course, they put me in touch with the support group here.*

*I started calling up and getting information and all. And then I was going through bad times and no matter what time it was there was always somebody there, whether it was 3:00 a.m. to answer my phone call, [to provide] information, and if they can point me, guide me into the right direction...Because I didn't know how to go about getting home care, Medicaid and everything, and they explained step by step what to do and I did that.*

*I went to a number of educational seminars, both about Alzheimer's itself, about financial planning. As a matter of fact, I ended up using the lawyer that did the seminar on financial planning to help us with the Medicaid process.*

It is important to note that virtually all of the activities cited by surrogates are activities regularly assumed and carried out in the course of the Association's on-going programs. What is different is that for the most part they have been focussed or channeled through one staff member employed for the demonstration.

Similar to the perceptual melding of roles between consumer directed care and the Concepts organization discussed above, the Alzheimer's Association is perceived by many surrogates as one and the same with the Supportive Intermediary. Most of the people involved in the CDPAP program are unaware of the unique role being played by the New York chapter in pioneering the Supportive Intermediary model.

The people interviewed had a high level of satisfaction with the services they receive from the Alzheimer's Association.

*Somebody is always there to talk to you, which is very good. They understand, they know what's going on... I think they're doing great ... I don't think I would add anything ... I never had any problems and whenever I needed them ... there was always somebody there.*

*As far as the [Alzheimer's] Association, I think they are a gift...Not only are they helpful for my mom, they are helpful for me and they're going to*

*be helpful for me in the long run...As far as the Foundation, it's a blessing, it's a god send, because it's something that I asked for.*

*I found them very, very helpful...very responsive.*

*I feel there's a deep sense of concern for helping caregivers of Alzheimer's patients and the comfort of knowing that.*

*They have been incredibly helpful in getting me to where I am now...They have been enormously helpful...I can't complain, even their literature is helpful.*

*I spent another maybe even 45 minutes on the phone on a Sunday morning with somebody from Alzheimer's and it was just when I was at the very beginning and she gave me so many resources. I remember she told me about the New York Foundation of Senior Citizens and they were the people that I ended up getting the hourly person to sit with my mother while I went to work. So I mean, the fact that I felt that I could call them, and they would come up with resources beyond them, they were incredible.*

The only complaint expressed with regard to the Alzheimer's Association involved a perceived lack of outreach to a minority group:

*The Alzheimer's Association I think is a great Association and they're doing the best they can...the Alzheimer's Association, they give the lectures and stuff... there's just one thing about the Alzheimer's Association that I feel is really lacking and that is they don't reach out to the Hispanic Community.*

It is obvious from the sample comments that surrogates have a high level of contentment and satisfaction with the services of the Alzheimer's Association. It is an organization that is accessible, flexible and responsive. It is an organization that provides people with the tools they need to understand and cope with a very frightening and confusing situation.

### **Medicaid and the NYC Human Resources Administration**

The majority of surrogates interviewed were pleasantly surprised by the lack of aggravation or confusion they experienced in dealing with the Medicaid process:

*I haven't had any problems with anyone ... I haven't even had a problem with the people from Medicaid*

Surrogate comments were overwhelmingly complimentary regarding the services received from Concepts and the Alzheimer's Association. One person reported a very negative interaction with the local Medicaid office. The primary problem appears to have been the HRA's lack of communication and failure to provide necessary information.

*Medicaid does not tell you anything at all. To get information out of them is like being a dentist and pulling teeth without any kind of Novocaine...Everything that I have to say is positive for Concepts. Everything I could possibly say for the Alzheimer's Foundation is positive; for the day care center, is positive. Now, you want to talk about HRA and the Medicaid division, everything that **you're** going to hear out of my mouth is going to be negative ....HRA and the majority of the people do not know how to speak English well, do not know how to read well, they don't know if they are coming or going, and they all want to pay specialists when it comes to Alzheimer's or whatever it might be; they know best...I found out about Concepts through the Alzheimer's Foundation. When I questioned Medicaid about it, the caseworker, whoever I dealt with, the people on the phone, nobody would give me any information about Concepts. They did not want to hear it.*

The predominant attitude regarding the City's HRA was neutral at best. Several surrogates mentioned an apparent lack of knowledge regarding the CDPAP option. Most felt that the main source for valuable information and support was Concepts and The Alzheimer's Association.

## **SUMMARY AND CONCLUSIONS**

Although this study is descriptive in nature, it has identified clear role indicators for both the surrogate and the Supportive Intermediary. It has delineated surrogates' perceptions about the role of the Supportive Intermediary and the Fiscal Intermediary. Finally the study described several of the key organizations that make up the complex network that implements the CDPAP. These are briefly summarized below:

### **Definition of Surrogate**

The five indicators of the surrogate role:

- assisting with activities of daily living,
- personnel management,
- business/financial management, and
- medical/therapeutic interventions
- socialization, including making plans and arrangements for pleasurable activities and opportunities for family and community interaction

Surrogates who only received twelve hours per day of assistance were more likely to feel the pressure of their responsibilities, citing that they do "everything" for their relative with dementia. Those who have access to 24 hour a day personal care support are more apt to perform management duties and feel somewhat better able to manage the added responsibilities.

### **Characteristics of Surrogate**

The surrogates in this small project are well educated and appear to be financially stable. Five of the fifteen surrogates were male relatives, the remaining ten being daughters. Their median age is 55 years, with a range from 33 to 83 years. The group were clearly desirous of having control over the home based service delivery received by their relative, and were willing to devote effort (primarily in the form of time) to making that happen. Their caretaker role evolved over time, increasing in direct proportion to the failing memory and dependency of their relative with dementia. The surrogates generally sought outside assistance when their relative's dementia resulted in dangerous behaviors, and when they could no longer manage the situation.

### **The Journey to Consumer Directed Care**

Surrogates found that applying for Medicaid, the gate to consumer directed home based care, was not a problematic process. However, several people cited the lack of publicity surrounding the program, noting that they came upon it by chance, or that professionals they encountered had no knowledge of the program. Similarly, a criticism of the Human Resources Administration was that workers had no knowledge of the consumer directed home care option.

### **Concepts of Independence, Inc. – The Fiscal Intermediary**

Concepts of Independence, Inc., the organization providing fiscal intermediary services associated with the consumer directed service option, was viewed positively by surrogates. In fact, they did not distinguish the notion of consumer directed services from the Concepts organization. It has only been since the Alzheimer's Association's involvement in consumer directed care that HRA and Concepts changed their policies to

allow non-directing consumers to access their services with surrogate assistance, although technically persons with dementia have been eligible for CDPAP since 1992.

### **The Alzheimer's Association/ NYC Chapter - The Supportive Intermediary**

Similarly, the role of Supportive Intermediary enabled people with dementia and their surrogates to access consumer directed services. The key activities of the Supportive Intermediary project are as follows:

- Information and referral
- Short term crisis counseling
- Peer group support meetings
- Application process support
- Community education
- Home care worker training in Alzheimer's and dementia
- Surrogate training in role skills (personnel management, fiscal administration, etc.)
- Advocate for the removal of barriers and continued access to consumer directed options.

However, these activities coincide with those of the Alzheimer's Association. Thus, it is not surprising that surrogates perceived the Supportive Intermediary project as one and the same with the Association, whose role in the community is to provide information and referral, advocacy, and support to families faced with complications associated with Alzheimer's disease. Indeed, it appears that what the Association has dubbed a "supportive intermediary service" is a collective term for what the Association has done traditionally.

Surrogates were very happy with the services they received from the Association, and often learned of consumer directed services through their involvement with the Association.

### **The Utilization of Consumer Directed Care**

- Consumer directed care is a little used option by families caring for people with Alzheimer's Disease who are eligible for Medicaid support. Fewer than 1.5 % of all persons in the home care program have opted for consumer directed care.
- CDPAP is not well known by those who would be the most likely sources of referral.
- Anecdotal reports from persons interviewed suggested the following barriers as possible factors in the low utilization of consumer directed care by all eligible persons including those with disabilities and dementia:
  - Routing procedures from hospitals that fail to inform patients of their option for consumer directed care;
  - Provider groups that resist change;
  - Aging caregivers, who themselves are struggling to maintain stability;
  - A perceived lack of privacy when dealing with Medicaid services;
  - Employee unions that fear the loss of organized attendant care workers;
  - Fiscal and system structures that act as barriers in the name of accountability; and
  - The disproportionate amount of work required by surrogates when participating in the CDPAP.

### **Conclusions, Implications and Recommendations**

1. Consumer Directed Personal Assistant Care is a little used option by families caring for people with Alzheimer' Disease eligible for Medicaid support.

The low level of usage for this group of persons tracks the election for consumer directed programming of *all* persons receiving support for Home Care personal assistance. Fewer than 1.5 % of all persons in the New York City home care program have opted for consumer directed programming. This has been ascribed to a variety of reasons:

- ◆ Lack of publicity and promotion by the Human Resources Administration both in the community (i.e. general public and prime agencies) and within and among its own staff.
- ◆ Hospitals in particular do not routinely assist individuals or families in electing consumer directed care.
- ◆ Provider agencies actively discourage or oppose the extension of consumer directed care.
- ◆ Labor organizations are opposed to consumer directed care.
- ◆ The inability to hire immediate relatives as personal assistants is a significant barrier to wider spread usage.
- ◆ The belief among family caregivers that handing over responsibility to a home care agency will relieve significantly the burden of managing and caring for a disabled relative.
- ◆ With reference to cognitively impaired persons, the requirement for a surrogate who will provide a daily presence and offer full and regular supervision effectively makes the option unavailable to lone persons, i.e. individuals without family members who can take on the substantial tasks associated with surrogate direction. This is a more common situation for single or widowed women whom are a considerable majority of the elderly disabled population.

The implications of factors extend to underlying policy, including rules, regulations, and perhaps legislation and/or state plan materials, ongoing program operations of the Human Resources Administration and the Alzheimer's Association, and research inquiring into the validity and weight such factors have in holding down participation.

Because *any* intervention which might promise significantly expanded utilization would require either major investment in public information efforts, marketing strategies,

and/or policy and program change, a primary effort should be undertaken through a systematic research effort to assess the reasons offered for low utilization. In particular, attention should be directed toward examining the factors in California, especially in densely populated urban areas, that have led to consumer-directed programs being the modal choice. Available data do not indicate the experience for home care services delivered to persons with Alzheimer's Disease and related disabilities.

2. Information about Consumer Directed Personal Assistant Program is not generally known by those who would be the most likely sources of referral.

While one would not expect the lay public to know the various kinds and dimensions of service that are available for people with cognitive disabilities, it is reasonable to expect that primary service givers and especially the agents and employees of the Human Resources Administration would know about the availability and eligibility requirements of the program so that people with disabilities and/or those caring for them could make informed choices among alternatives. As noted, respondents indicated that knowledge about the program was not general. Perhaps especially important was the information that when an individual leaves a hospital for home and is referred for Home Care Services, the procedure avoids processing through the CASA which is the primary entry point for Consumer Directed Home Care. However, even within the CASA it appears that Consumer Directed Services are not always offered or explained. However, it must be pointed out that staffing in the CASAs runs 20 % below the quotas for Case Managers---and that with an assumed caseload size of 155!

Two possible interventions are suggested to increase targeted information dissemination:

- a. Development and conduct of training sessions and materials for CASA Case Managers through a cooperative program between the City and the Alzheimer's Association. However, such a program is not likely to be undertaken successfully

in the absence of improved staffing levels in the CASAs. Consideration should be given to joint planning between the Association and the City to achieve both better staffing levels and improved training.

- b. Development of new procedures which will route hospital discharges with provision for Home Care Services through the CASAs in order to assure an offer of CDPAP to eligible persons. This may require the involvement of the Association with the Hospital Association as well as the City. Such procedures will necessarily require associated training programs and materials.
3. Consumer Directed Personal Assistance Program for people with cognitive disabilities requires the presence and involvement of a surrogate, deeply committed, available to carry out substantial tasks of training, supervision, and maintenance tasks for the disabled person. Surrogates require a wide range of supportive services for themselves and those they care for. Such services extend beyond the range of capabilities of the Alzheimer's Association.

Such surrogates must either possess or learn management skills necessary for the maintenance of the household with a cognitively disabled individual, the direction of a Personal Assistant, and the coordination of a variety of health and social services which may include periodic medical and nursing assessments, oversight of pharmaceutical regimens, arrangement for transportation services, attendance at community based activities, and similar matters. To carry out the normal tasks involved in being a surrogate decision maker requires in addition to skills noted above, the time, energy, and resources essential to maintaining the surrogate's life.

Because Alzheimer's Disease and similar dementias are almost always associated with late life, surrogates, who are almost always family members, are often elderly themselves (e.g. spouses or siblings), may have economic and physical problems, or, if adult children, may be working in full time jobs. If the person with the disability lives with the surrogate, there is always the question whether the environment supports or diminishes the hoped for benefits of home based care. Crowded living arrangements in substandard

housing beset by security problems may not always offer the best opportunities the disabled person.

Therefore, while consumer directed home care may be the protocol of choice *all things being equal*, the determinations of putting together the combinations on social, medical, and psychological interventions requires sensitive and sophisticated counseling for which, it appears, the Alzheimer's Association is especially well-suited. However, the Association can, in no way, take on that role for a significant proportion of potentially eligible persons. Furthermore, any successful program generating higher levels of utilization of the CDPAP program for cognitively disabled persons must be accompanied by the array of substantive support programs which may include transportation, day care services, readily available support group services, adequate outpatient medical services, respite care, and others. Such support programs will necessarily involve a wide variety of public and private agencies. This is the lesson which experience in developmental disabilities has taught and which ought to be applied here.

Furthermore, even within the limited resources of the Alzheimer's Association, it would seem to require a forthright commitment to direct service to both the disabled and their surrogates. While service *is* provided currently, it appears to be incidental to the ostensible primary roles of information and referral, and is not regarded as a co-equal program element, much less a primary one.

4. With but a single exception, surrogates who had been involved with the Supportive Intermediary project gave high praise for the support and service that had been received from the Association.

Surrogates did not distinguish between and among staff or services which they regarded as helpful and supportive. In effect, surrogates saw *all* of the Association's activities as

being part of the special project. Surrogates recognized the complexity of the systems they were dealing with but seemed to accept that complexity as "just the way things are". Surprisingly, they offered few complaints about the time or the processes required to establish Medicaid eligibility, although it appeared to evaluators that in a number of cases complaints would have been well justified. Indeed, it was more common for our respondents to reply that the Medicaid application "went smoothly".

5. Significant extension of the Consumer Directed option to persons with Alzheimer's Disease and similar disabilities requires a broad and massive advocacy effort extending beyond the capacity of the Alzheimer's Association.

The Director of the Supportive Intermediary Project has, in conjunction with other staff members in the Association, carried out a wide variety of special programs for potential surrogates, community agency personnel, and professionals servicing people with cognitive disabilities. These programs are consistent with the activities historically provided by the Association. However, when viewed in the context of the population at risk sought to be reached, the uninformed and ill informed professional communities ostensibly serving people with Alzheimer's Disease and related dementias, it is clear that the problem requires a massive coordinated public education, advocacy, and marketing effort.

Special attention should be directed to non-English speaking populations which are substantial in New York City. Agencies cannot possibly address the multitude of language demand unless an agency happens to specialize in a particular ethnic group. Consumers are in the best position to recruit through their churches and other ethnic associations. The Alzheimer's Association does not have the capacity within its staff to respond to populations which may require help in Spanish, Russian Ukrainian, Hmung, Vietnamese, Korean, Chinese dialects, and on and on.

This suggests avenues of planning effort for the Association, and its national parent, the National Alzheimer's Association. These avenues include significant involvement with Nationality Service Centers, churches serving particular nationality groups, and others within the city to reach out to these groups.

At the more general level, the Association could be working directly with the organizations representing people with physical disabilities, e.g. Centers for Independent Living, and the specific disability associations. Both the Independent Living Movement and the Developmental Disabilities Movement have engaged in vigorous multi-pronged advocacy efforts that have gone far beyond seeking additional financing through the programs primarily affecting them. They have addressed issues of access to service (well beyond physical access), issues of discrimination, and array of issues affecting the quality of life, viz. education, housing, transportation, etc. each of which may involve different agencies and funding streams. Finally, they have undertaken their advocacy with vigor, and perhaps, most significantly through grass-roots, community based efforts in which professional organizations have been subordinate to consumers and consumer expression. They offer useful models to emulate.

6. Programs under the aegis of the Area Agency on Aging and Managed Care may be two important elements in the future utilization of CDPAP for people with Alzheimer's Disease.

There are two important exogenous factors which may have an important impact on the utilization of the Consumer Directed Personal Assistance Program for people with cognitive disabilities: (1) programs furnished through the Area Agency on Aging; and (2) the impact of managed care. Any suggestion of their impact is sheer speculation. The managed care element has been raised by both the public agency and the fiscal intermediary. Managed care's impact on health care delivery has been palpable. Because the Personal Assistance

Program of Home Care contains health, personal care and social services, it is difficult to predict what might occur, although it is not unreasonable to suggest that there will be an inclination to medicalize the program, which in turn may so alter the benefit structure that New York City's sophisticated approach to home care may fall victim to the trend of long term care institutionalization for the elderly. How the Area Agency on Aging can fit in is difficult to say. Nationally, programs on Aging have stayed away from programs for the cognitively disabled.

What may be in the future is difficult to say.

Overall, the effort in New York City is instructive. It is unique in terms of the densely populated, multi-ethnic population served, the generosity of the benefit structure, the availability of an effective fiscal intermediary structure, and the interest of the Alzheimer's Association. On the other hand, the program shares common characteristics with other similar efforts around the country: an under-staffed public benefit agency, inadequate in number and substance, related support services, relatively quiescent advocacy efforts, particularly within the Aging Community, poor understanding among the related service agencies, e.g. hospitals, medical services, social service agencies, legal services, and mental health agencies of the ethical imperatives and programmatic benefits of consumer directed services for persons with Alzheimer's Disease and related disabilities.

Thus, the project deserves considerable attention, less to support the notion that people with dementing illnesses and their surrogates can benefit from consumer direction, than to suggest the substantial kind of effort that is required to make the program the program of choice.

Careful review of all of the factors the demonstration project exposes and development of broad-based advocacy and action plans based upon that review offer the promise of success for the quiet revolution.

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## MEMORANDUM

**To: Marshall Kapp**

**From: Elias S. Cohen**

**Date: February 12, 2000**

**Re: MS Queries - 2/9/00 e-mail "Manuscript"**

1. Re "proxemically" - already dealt with in earlier e-mail
2. P. 10, line 4: Fuller cite for OBRA: The citation should appear after the words, "Medical Assistance" in line six and should read:
3. 42 U.S.C. 1396(a)(10)(ii)(VI - VII), and 42 U.S.C.1396d(a)(xi)(24).
4. P. 21, Last Paragraph - Verify issuance of Regs by Atty Gen. The relevant regulations appear in 28CFR35 which lays out among other things responsibilities of the Department of Justice for Enforcement.
5. P. 23, Line 4 - There is no Ladd, 1998. The reference should read Ladd-b (1999)
6. P. 23, Line 10 - The reference should read: Ladd -a (1999)
7. P. 25, Line 3 - The reference should read: Ladd - c (1999). This will add a new reference as follows:

Ladd, R. C. -c with Kane, R. L. and Kane, R. A. (1999) Draft, Table 33 - Medicaid Home and Community Based Services to Medicaid LTC Cases 1996,*State LTC Profiles Report, 1966: Balancing Long Term Care*, Division of Health Services Research and Policy, School of Public Health, University of Minnesota.

8. P. 29 Indeed, there *was* something omitted from your copy. The following should precede the bullets:

In broad brush strokes, one might say that New York City's program was the result of major currents swirling about the disabled elderly over the last half century. These currents may be roughly delineated as follows:

Regarding References:

Abel page numbers: 42-64.

Dill page numbers: 8-41

Names in addition to Harrington are:

LaPlante, M.  
Newcomer, R. J.  
Bedney, B.  
Shostak, S.  
Summers, P.  
Weinberg, J.  
Basnett, I.

Page numbers for Horstman are: 215-236

Re citation for Johnson: Her article runs from p. 12 to 14 and is continued to and completed on p.35. I want to cite the entire article, but am not sure how to indicate the page numbers. Help!

Re Page Numbers for Tollen. The name of the Journal was incomplete. The correct reference should read as follows:

Tollen, W. B. (1964) Historical Résumé of Public Welfare in the United States, *J of Jewish Communal Service*, XL(4) 355-364.