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Friends of the family: A socioeconomic profile of unionized home care workers

Unterbach, Davida Golland, D.S.W.

City University of New York, 1992

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FRIENDS OF THE FAMILY

A Socio-Economic Profile of Unionized Home Care Workers

by
Davida Unterbach

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

1992

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This manuscript has been read and accepted for the Graduate Faculty in Social Welfare in satisfaction of the dissertation requirement for the degree of Doctor of Social Welfare.

1/9/92
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Abstract

FRIENDS OF THE FAMILY

A Socio-Economic Profile of
Unionized Home Care Workers

by

D. Unterbach

Advisor: Professor Paul Kurzman

Medicaid funded in-home care will continue to be a focus of national attention, an arena of policy debate, a challenge to program and a call to creative practice. This study focuses on a crucial element of home care: the women who provide the vast majority of services to the functionally disabled citizens of New York City: elderly, adults and children.

The results of this socio-economic demographic study of unionized home care workers reveal that home care workers must have their basic needs met if quality care is to be rendered and sustained.

Acknowledgements

This work could not have been completed without the generous input of my "formal" and "informal" systems.

I am grateful to Dr. Paul Kurzman, the Committee Chair, leader in industrial welfare, whose leadership, grounded in his commitment to improving the work lives of the American labor force, has been realized in a wide variety of public arenas; Dr. Mildred Mailick, whose contribution to the field of social health is shown in her writing, teaching and character; Dr. Rebecca Donovan, whose enthusiasm for this project resulted in her initial and subsequent studies; and to Dean Harold Lewis. It has been my particular honor to have been both his student and, at times, a member of his staff. When the quintessential welfare history is written, Harold Lewis' vision, leadership, brilliance and kindness will shine even more brightly than the glow he consistently radiates.

I have had the great good fortune of ongoing encouragement by two outstanding social workers who are models of professionalism: Dr. Rose Dobrof of Hunter - Brookdale Center on Aging, and Dr. Robert Salmon of Hunter College School of Social Work.

The cooperation of Local 1199, the Home Care Council, agency executives, and mostly the noble women who

eagerly participated in this study allowed the study to be conducted.

I have been blessed with friends who suffered through this process and gave emotional and intellectual support throughout. Dr. Jan Poppendieck and Dr. Micki Silverman are the two women whom I relied upon for comment, insight and innovation. Dr. Steve Silverman, Dr. Jeff Golland and Jill Allweiss, MSW, made up the rest of the team.

George Ziskind, the jazz pianist, processed my words while suffering my hystrionics, and Dick Faust was always ready with incalculable calculogic.

I would not have been able to complete this tome were it not for the love and remarkable patience of Arnold Unterbach, my husband of 25 years and the father of our son, Joshua; he listened to every revision of every revision.

This dissertation is dedicated to my father, an organizer of the shoe union, who would have been so proud, and to my mother, Rose Finkelstein Golland who *is* so proud.

TABLE OF CONTENTS

Copyright ii
Approval iii
Abstract iv
Acknowledgements v
Table of Contents vii

CHAPTER I An Overview of Home Care 1
Scope of the Issue 4
The Home Attendant 6
Sub Group of the Working Poor 9
Unmet Need 11
Relevance to the Profession 13
The Study 15
Underlying Assumptions 16
Conditions to be Altered 18

CHAPTER II Review of Related Liteature 21

Part I

History of Publicly Funded Home Care 21
Demographics - The Graying of America 27
Family as Informal Caregiver 32
Provision: Medicare and Medicaid 35
Social Health 40
Service Delivery Mechanism and Program Administration 44
History of the Economics of Health Care Expenditures 48
Policy Alternatives 54

Part II

The Needs of Home Care Clients 56
Home Care Programs, Home Attendants and Home Health Aides 62
Home Attendants, Homemakers, Home Health Aides; Status and Attrition 67
Quality 72
Recruitment 77

CHAPTER III Methodology 79

Part I

Historic/Contextual Development of the Methodology . 80
Contact Work with Local 1199 83
Contingency Planning 87
The Home Care Council 93
Vendor Home Attendant Programs 94
Benefits of the Study 97

Part II

Technical Aspects of the Study 100
Design 100
Target Population 101
Sample Selection 101
The Data Collection Instrument 102
Data Collection and Procedures 104
Strengths and Limitations 109

CHAPTER IV Findings 115

Demographic Characteristics 116
Economic Characteristics 122
Poverty Level 128
Eligibility for Public Benefits 135
Health 143
Correlates of Stress Related Illnesses 150
Multivariate Analysis 158
Summary of Key Findings 161

CHAPTER V Summary and Implications 171

The Home Care Worker 171
Race, Gender, Poverty and Health 175
The Family 181
Long Term Care Policy 185
Economic Costs and Consequences 186
Social Costs and Consequences 189
Medicare 191
Medicaid 192
Unionization 194
Recommendations 196
Conclusion 203

EPILOGUE 205

APPENDICES

Appendix A Welfare vs. Work 219
Appendix B Letter of Endorsement from 220
Local 1199 to Agencies
Appendix C Letter of Endorsement - 221
Home Care Council President
Appendix D Letter of Request to the Agency 222
Appendix E The Instrument 223
Appendix F Instructions to Study Participants . . . 224

BIBLIOGRAPHY 228

Chapter I

An Overview of Home Care

INTRODUCTION

This study is an exploratory survey of a large and growing segment of the health care industry: Home Attendants. It investigates the demographics, economics and reported incidence of stress-related illnesses incurred by the women working in community-based, Local 1199, unionized, Home Attendant Programs in New York City. The study looks at the questions: who are the women who help the sickest, poorest and oldest New Yorkers, and what help do these helpers need?

Relatively little attention has been focused on the home attendant occupation - the mainstay of community-based long term care despite demographic forecasts of an expansion in the need for in-home services and, therefore, service providers. One can only speculate as to why this cohort has been relatively neglected; however, the fact that this group is comprised of women and mothers, minorities of color and immigrants is undoubtedly a factor.

Home Attendants are on the lowest rung of the health care hierarchy, followed by home makers and then home health aides. As is true of other service oriented fields,

(day care, foster care, nurses aides, school aides etc.) they provide the greatest number of hours of direct care while receiving the least compensation, least training and supervision and even lack the basic social supports that are inherent if one works in an institutional setting.

It is noteworthy that the only formal requirement for this job is passing a physical examination and brief written exam testing literacy. It is as if women are assumed to have innate qualities and abilities as caretakers. It is as if caretaking is a task that does not require any special skills. Caretaking, seen as a traditional role for women, is afforded little recognition, status, or reward.

There is a good deal of data documenting the stresses associated with family caregiving.[1,2,3,4] These stresses include stress related illness, job interruption, depression, fatigue, fears and guilt. Furthermore it

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1 Horowitz, A. "The Impact of Caregiving to the Chronically Ill Aged." D.S.W. dissertation. Columbia University, 1981.

2 Archbold, P.G. "An Analysis of Parent Caring on Women." Home Health Care Services Quarterly 3, no. 2 (Summer, 1982): 5-25.

3 Lebowitz, B. "Family Care Giving in Old Age." Hospital and Community Psychiatry, 36, no. 2 (May, 1985): 175-193.

4 Stoller, E. "Elder Caregivers' Relationship in Shared Households." Research on Aging 2 (June, 1985): 175-193.

has been established that the term "caregiving" most often translates into women caring for their relatives and their in-laws.[5] Is it not reasonable to assume that the formal caregivers, the Home Attendants, might also encounter similar stresses as job related?

The unionization of this work force, begun in 1981, provided an opportunity for a group of thousands of minority women workers to have an institution which could advocate on their behalf. It further created an opportunity for social work to apply its knowledge, skills and values to offer service to a low income, minority, female workforce which has chosen work over welfare, independence over dependence, service over seclusion.

Prior to unionization, Home Attendants worked as independent workers directly contracted by New York City's Human Resources Administration (HRA). As the numbers of home care cases increased, so too did the number of workers needed. The City altered its policy of direct service provision to vendorizing or sub-contracting.

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5 Bromberg, E. "Mother-Daughter Relationships in Later Life: The Effect of Quality of Relationship Upon Mutual Aid," Journal of Gerontological Social Work 6, no. 1, (Fall 1983): 75-92.

During the last eight or nine years the City, under HRA, through the Home Care Services Program, a sub-department of the Medical Assistance Program (MAP) has overseen and managed contracts with some 62 vendor agencies known as Home Attendant Programs (HAPs) or vendor programs. "Vendorization, the provision of personal health care services at the local level (created) an organized system of care designed by local governments to provide managed care at reasonable costs."[6] One question explored in this study is: are these "reasonable costs" coming at the expense and health of the workers?

SCOPE OF THE ISSUE

Publicly-funded community-based Long Term In-Home Care to the functionally disabled and elderly in New York State and primarily in New York City can be seen as a social experiment. "Eighty percent of all national home health and personal care services are rendered in this State with 73% provided in New York City."[7] Home Care in New York City can be seen as the laboratory which Federal legislators will review when planning future policies. In-home care has

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6 Benjamin, A.E. "Trends and Issues in the Provision of Home Health Care: Local Governments in a Competitive Environment." Journal of Public Policy, 7, no. 7, (1986): 480-494, p. 492.

7 Planning for Home Care in New York State. Annual Seminar. New York State Council on Home Care Services (Sept. 1983) p. 9.

become a cultural, social and economic phenomenon that will expand as increased family mobility, changing family composition, increases in the absolute and proportionate number of old people continue to be a fact of society. We might predict a decrease in available informal supports: the potential of catastrophic medical expenses exempts no one, regardless of class, from the eventual need for help. The experience of New York City can be seen as a pilot project for the nation and the Home Attendant is a pivotal aspect of that experiment.

As of November 1988 the number of in-home cases managed by the Human Resources Administration of the City of New York was 45,633. Of these, 34,132 cases (including 343 persons with AIDS) are serviced through Home Attendant Programs. The remaining 11,501 cases are served through certified Home Health Aide Agencies (761), the Lombardi Bill Nursing Home Without Walls (3,006) and Housekeepers (7,734).[8,9] By best estimates there are some 42,000-45,000 HA's serving the 34,132 poor, sick, dependent Medicaid

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[8] Black, J., Assistant Director of Program Design for Medical Assistance Program, and Collwyn Butler, Director of Division of Home Attendant Contracts for Services. (Telephone interview) December, 1988.

[9] Surpin, R. and Grumm, F., "Building the Home Care Triangle: Clients and Families, Paraprofessionals and Agencies in Partnership with Government." A Report of the New York City Home Care Work Group. January 1990.

home care clients. "In 1988 New York City home care program service costs exceeded $850 million."[10] What is known is that Medicaid funded in-home care was the largest single budget item for Medicaid in New York State. In 1982, the cost to the state was $300 million and in 1984 $502 million dollars was spent on the provision of this service.[11]

THE HOME ATTENDANT

The first demographic profile of the HA was completed by Dr. Rebecca Donovan, of Hunter College School of Social Work, City University of New York, in 1986.[12] [13] A summary of her seminal work reveals a profile of the HA as a minority woman, immigrant, living in poverty, often the head of household raising children, while working in a dead end job which lacks the usual job security and fringe benefits package customary for health care workers. Approximately one third of the entire HA workforce in New York City is represented by Local 1199, of the Drug, Hospital and Health Care Employees Union. Two other unions represent home attendants:

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[10] Surpin & Grumm, Ibid., ii

[11] Caro, F. The Structure and Operation of New York City Home Care Programs. New York: Community Service Society Publication, 1983.

[12] Donovan, R. "The Health and Social Needs of Home Care Workers." Preliminary Report. Summary of Survey Findings 1985 TMs.

[13] Donovan, R. "Stress in the Workplace: A Framework for Research and Practice." Social Casework 5 (May 1987): 257-272.

Local 1707 of the Community and Social Agency Employees Union and Local 32B-J of the Service Employees International Union. The percentage of non-unionized HA's is not known.

Employment in minimum wage jobs often translates into creating heightened income and medical needs as well as omitting formal access to psycho-social-medical-legal-educational services. The workers may stand to jeopardize their health and that of their children. Minor increases in rent or sudden acute illness of self or child, and lack of customary fringe benefits, can have catastrophic results: The enslavement and humiliation built into the fabric of Public Assistance, abuse or neglect of children or homelessness. They earn "$4.45 an hour or less and start at $4.15 which means that even by working full time, most are officially poor."[14] The starting wage of $4.14 an hour is only 25 cents over the then minimum wage.

It stands to reason that if sufficient economic and social supports continue to be denied to this marginal work force, as an institutionalized condition of employment, the social and health consequences and costs will be grave to the workers, their families and the quality of the service they render to clients. It may be that some HA's are not doing

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14 "New York City, There Are Many Ways To Be Poor," The New York Times, March 5, 1989, p. 6(A).

their jobs well. It is fair to assume that deprived of formal incentives and tangible rewards some HA's are demoralized. It seems reasonable that if quality care is an expectation, then ample salary, physical well being, certainty that their children are safe and supervised are prerequisites to this expectation being realized. Anything less than these conditions of employment speaks to an insidious contempt for the care of our old and disabled as well as the Home Attendant.

What the HA does in her daily work is more elaborate than "personal care and household tasks." In addition to the chore services that comprise "activities of daily living" (shopping, cooking, cleaning and escorting, helping with grooming and bathing) she fulfills numerous social functions. Her presence results in decreasing the social isolation that often accompanies disability and old age. She can improve the quality of a client's life, she may be the only human contact in any given week, provides stimulation, develops a relationship and in some cases adopts the client as if she were a member of the family. Additionally, she helps maintain people in the community, alerts personnel specialists to medical or psychological changes and lessens the burden on whatever family may exist. While there is an expectation that the HA is a supplement to care, in fact they are often the primary person involved with the client. Yet

while assuming enormous responsibility, the job is devoid of supervision that might assure a greater quality of care.

It has already been established that "even among those who got off Aid to Families with Dependent Children (AFDC), 40% continue to have incomes below the poverty level and about one third subsequently return to AFDC."[15] On a policy level, one must wonder about the disincentives to work created by this dilemma. An alternative definition of in-home care might be to see it as a public works program that provides stressful, isolated work, limited income, minimal health coverage and no employee assistance while juxtaposing one group of needy women with another.

A SUB-GROUP OF THE WORKING POOR

While HA's are an important occupational arena to survey, they can be understood as but one sub-group of a larger group of working poor and poor working women. "According to the National Commission of Working Poor Women, 80% of women in the work force are employed at low skilled, low wage jobs."[16] Furthermore "two out of three poor adults are

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15 Kamerman, S. "Young, Poor and A Mother Alone: Problems and Possible Solutions," in Services to Young Families. American Public Welfare Association, 1985.

16 Lefkowitz, R., & Withorn, A. For Crying Out Loud: Women and Poverty in the United States. Cleveland, OH: The Pilgrim Press, 1986.

women."[17] While "women are more likely to carry primary responsibility for supporting themselves and their children as a result of rising divorce rates and non-marital childbirths, they remain locked into dead end jobs with wages too low to support themselves let alone sustain a family."[18] Clearly, wages for most women in the work force are neither living wages nor family wages, despite the number who are sole breadwinners.

The numbers of working poor in New York City, those workers whose incomes fell below the Federally established poverty line of $11,611 for a family of four, are comparable to the number of recipients of Public Assistance - each group is approximately one million people. A job therefore "does not necessarily mean that a family escapes poverty."[19]

In 1988 service jobs were far fewer than the numbers of job applicants, a clear indication that the "unskilled" are in fact motivated to work. There were 601 applicants for 60 teachers' aide jobs which pay $4.50 an hour. Likewise, 6,168 women applied for the 495 Home Attendant jobs which start at $4.15 an hour. 2,402 people applied for 135 nurses' aides jobs and 31,204 people sought the 1,532

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[17] Ibid., 19.

[18] Ibid., 20.

[19] New York Times. Ibid.

minimum wage job as hand packagers of manufactured goods.[20]*

According to a Community Services Society study cited in the New York Times,[21] when the budget of an AFDC mother of two children, one too young for school, was compared to her working counterpart with two school aged children, the monthly income differential was $47 a month - or less than $10 a week. (See appendix A)

One might wonder about how people, primarily women, maintain their desire to work, their independence and determination in light of the deprivation of resources, access and incentives necessary for basic survival.

THE UNMET NEED

While the HA's role is as an employee of vendorized Home Attendant Programs, it is a thesis of this study that an

* For a detailed discussion on the creation of a surplus labor force see Sassen-Koob "Exporting Capital and Importing Labor: The Place of Women," in Caribbean and Latin American Migration to the United States: The Female Experience, Bryce-Laporte & Mortimer (Eds.), Smithsonian, Washington, D.C. 1981, pp. 203-239. She shows how the Caribbean Immigration of the mid 1960's allowed for low wage jobs to "absorb a large share of the increased female immigrants from the Caribbean, Latin America and Southeast Asia." (p. 219).

20 Ibid.

21 Ibid.

this work force is comprised of women who have elected, within a narrow window of opportunity and limited options, to work in "marginal" health care jobs providing services essential to the well being of their clients. It is assumed that they encounter all of the adjustment difficulties associated with changes of land, language and culture that are part of the experience of immigration. It is further assumed that there is currently no provision or mechanism that assures access to or utilization of the array of health and social services that exist. Given the stresses associated with poverty, wages, immigration, single parenthood, marginal work, minority status, inadequate training and education, lack of pension and career ladder and inadequate medical coverage that Donovan[22] found, it is assumed that the quality of their life, health and circumstances of living are in need of improvement.

Like so many of the elderly, who are too "rich" to qualify for medicaid and too poor to pay for services, there is a true irony to the fact that HA's are generally too "rich" to qualify for public benefits but earn too little to purchase food, rent, clothing and health care on their own. Social work is mandated to identify these gaps in social policy and then create and utilize resources which bridge those gaps.

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22 Donovan "Stress in the Workplace: A Framework for Research and Practice." Ibid., 274.

Further, it is assumed that these life stresses impact on the quality of life of their children and on the work which they provide to clients who have no other options. It is these facts which provide the rationale for the formulation of the problem and provides justification for this study.

RELEVANCE TO THE PROFESSION

The rationale for selecting this population is grounded in values basic to the social work profession. Values, "the fulcrum"[23] of the profession, the energy which drives the investment of skill and knowledge, suggest the necessity and appropriateness of targeting the HA as a focus of work. There are conditions present in the life of the HA which should be changed and can be changed.[24]

Analysis of the stresses which are characteristic of the "circumstances of living and the quality of life"[25] requires systematic intervention in order to prevent or

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[23] Reamer, F. Dilemmas in Social Service. New York: Columbia University Press, 1982.

[24] Lewis, H. The Intellectual Base of Social Work Practice: Tools for Thought in a Helping Profession. New York: The Haworth Press, 1982.

[25] Gil, D. Unraveling Social Policy. Rochester, VT: Schenkman Publishers, 1976.

decrease dysfunction. Poverty, gender, race, single parenting and immigration have been the historic focus of social work intervention. Work which benefits society yet provides inadequate incentives ought be improved. Dead end jobs which are inherently isolating and require reconceptualization.[26]

As professionals, we are ethically mandated to work toward a more humanitarian and just society where cooperation supercedes competition. Sharing the benefits of our knowledge and skill with groups who have encountered barriers to economic, health and educational opportunity is inherent in our mission.

A study of HA's creates an opportunity to operationalize beliefs into creative action through the provision of supports necessary to facilitate the independence of individuals, families and groups of workers. The allocation of limited resources to a group which walks the tightrope between dependence and independence is further justified by the nature of the work that the HA performs.

To the extent to which the HA can be recognized as an integral part of the service delivery system of home care, as a health care provider, focus on her needs demonstrates a

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[26] Chapter 5 will elaborate on the recommendation to create a generic title and build in a career ladder.

"unity of action."[27] Not only can her own needs be met, but her ability to perform care giving functions on the job and in her own family may be enhanced.

THE STUDY

It is with this background that the stage is set for the proposed study. The objectives of this study are several. They are: to discover the existing incidence of stress related disease incurred, to gain knowledge of the HA's true economic circumstance, and to expand our knowledge of her socio-demographic profile - age, number of children, marital status, country of origin and educational background. Additionally, the study describes the process of forming a working alliance with the union and looks at the role of unionization as a route to empowerment. Implicit in the study is the social policy impact of action-based research and the synergistic opportunities posed by inter-agency collaboration. Methodologically, attention will be paid to the principles and processes of inter-organizational collaboration that allow such a project to be conducted. This study will collect data and report on qualitative and quantitative findings.

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27 Lewis, H. "Ethical Assessment" Social Casework, 25, no. 3 (March 1986): 376-387.

ASSUMPTIONS

This study makes several assumptions about the target population of unionized home care workers.

A summary of Donovan's findings of Local 1199 home attendants[28] indicates that: 99% of the population is female, average age is 47, 53% are currently single, 64% have not completed high school, 96% are minority of color, 46% are foreign born--preponderantly Caribbean born, many of whom are Spanish and Creole speaking, and 85% are raising children. Given the fact that Donovan's study was the first to target this cohort, a study which provides additional data serves to better inform planners in determining social action. This study assumes that this cohort may incur a higher incidence of stress-related illness than the general population of women. It assumes that in the process of data collection, a network of the union, the university and the home care council can become more tightly woven, allowing inter-organization collaboration to be exerted on policy and program decision and directions.

This study assumes that many workers do not know about their existing medical benefits. It assumes, based on their income and family size, that some workers may be eligi-

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28 Donovan, "Health and Social Needs of Home Care Workers." Ibid.

ble for Medicaid and/or public assistance and are not receiving these entitlements. It assumes that workers may either miss time on the job due to illness or that they may go to work too ill to work, thus compromising their health and that of their clients. It assumes that improved health benefits will be perceived to be of great importance. If health care costs are high, yet can be offset by extended coverage, then disposable income may be increased.

It assumes that when child care costs, rent, carfare, and medical costs are computed that actual disposable income renders this population far more impoverished than actual wages would suggest.

It assumes that this is a stable workforce and that part time workers would prefer full time employment.

More generally, it is assumed that this cohort represents the historical concern of the profession: minority and immigrant women who are low paid, raising children, who are vulnerable to the cycle of poverty. Their work as health care providers makes them clients and colleagues in one. The fact that they provide services to the parents of many middle class adults broadens the constituency interested in improving the lives of home attendants.

It is a fact that home care will be an area of growing national interest given the projected demographics of the aging population. Social work ought to exert an influence on the conditions of working for a work force that will grow.

While this cohort is of interest in and of themselves, they are but one representative group of the working poor. Knowledge gleaned from this study may bring greater attention to other human service work forces as well as to industries in which women predominate as workers.

CONDITIONS TO BE ALTERED

The conditions to be altered as a consequence of this study span the levels of social welfare concern. By expanding the knowledge base, an opportunity is created to bring greater attention to the plight of these working poor women. If social work evolves by defining emerging gaps and groups in need, it follows that refining our understanding of the needs of this population serves the mission of the profession. Attention to the conditions of life experienced by working poor women who work in the health care system highlights the larger issues of the home care system -- a system predicted to expand nationally.

Documentation of needs may underscore the central service role performed by these workers. It may be that as a

result of being motivated to full-time work, home attendants become economically ineligible for the comprehensive coverage provided by Medicaid. This fact could support legislation proposed on the federal level for a minimum health-care coverage for all workers. This study could bulwark the arguments advanced by proponents of such policy reforms as "tax subsidized fringe benefits."[29]

As a consequence of the methodology (see chapter 3) study participants will be informed about and encouraged to use the newly created social work services program established at Local 1199. The union may have an increased utilization of this service, allowing members to experience a direct benefit of their membership and perhaps improving their perception of their union.

Social workers are at the crossroads of a field that has hitherto been influenced by medical, bureaucratic and political forces relatively devoid of social work input. Seizing the opportunity created through the recognition of the current gap in knowledge about home care workers may reverberate in important ways across micro and macro levels of the social structure.

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29 Parham, T.N.J. "A Special Concern Demands Special Responses" in Services to Young Families. Washington, D.C.: American Public Welfare Association, 1985.

Social welfare research is a form of social action. By definition social welfare research is non-linear and may help in generating policy and program through the actual evaluation of data as well as by the formal and informal processes inherent in inter-organizational collaboration.

The next chapter will review the relevant literature.

Chapter II

Literature Review

PART I - INTRODUCTION

The literature review will present the history, provision, policy and policy alternatives of publicly funded home care in order to describe the evolutionary process that created the home care industry, and in turn, its work force.

The needs of home care clients and their families along with the literature about Home Care Programs, Home Health Aides and Home Attendants will be reviewed in Part II of this chapter in order to be informed of the state of the knowledge of this growing health care industry.

THE HISTORY OF PUBLICLY FUNDED HOME CARE

A historic review of the policies, administrative structure, economics and demographics of long term care creates a backdrop to this study.

The passage in 1965 of Titles 18 & 19 of the Social Security Act, Medicare and Medicaid, respectively, represented an effort that had its origins in the policies enunciated by Teddy Roosevelt's Progressive Party in 1912.[1] It is part of the history and tradition of the American

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[1] Mundinger, M.O. The Home Care Controversy: Too Little, Too Late. Gaithersberg, MD: Aspen Press, 1983.

political process that change occurs over time, as a consequence of compromise, through an interplay of dynamic social, economic, demographic and political forces, which culminate in changes in policy.[2] Once legislated policies go through various phases of implementation. As conditions change, policies get modified or reformed, hopefully, to reflect intent and need.

During the early 1930's, Franklin D. Roosevelt's Committee on Economic Security recommended the inclusion of health insurance benefits for the elderly as part of the Social Security Act. Political consideration for the passage of the Social Security Act allowed FDR to endorse national medical insurance in principle only. In essence, to achieve the momentous passage of the Social Security Act the medical insurance component was compromised.

From the mid 1930's to the 1940's, health bills introduced during the Roosevelt and Truman administrations were unable to gain sufficient support. Conservative counter-forces combined with the ethos of the time were successful in forestalling new federal health insurance policies.

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[2] Cohen, D. "Loss As a Theme in Social Policy." Harvard Educational Review, 46, no. 3 (November, 1976): 298-330.

By the early 1960's, as a consequence of state and federal hearings, the fact that the cost of health care was documented as the primary problem of the aged, the Kennedy-Nixon debate on health insurance, the 1961 White House Conference on Aging, the growing financial crises of hospitals, the Civil Rights movement and the increase in the absolute and proportionate numbers of people surviving beyond the age of 65, Medicare and Medicaid, universal and categorical health plans, were enacted into law.

The "Graying of America" was one factor that led to the enactment of Medicare and Medicaid legislation, Titles 18 and 19 of the 1965 Social Security Acts. As a consequence of Medicaid's in-home care provision, a new tier of direct service provider was created - the Home Attendant. If we are to meet the needs of the functionally disabled who are living in the community, 81% of whom are elderly[3] then it seems logical that attention be focused on the conditions of life and conditions of work that the direct care providers experience.

More recently, in response to the growing numbers of older people in need of home care, there have been a variety of legislative acts indicating growing support for

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[3] Calvin, B. and Nelson, K. Home Care in New York State: A Descriptive Analysis Home Care Association of New York, May, 1979.

home care. Title XX of the Social Security Act, enacted in 1974, and implemented in 1975, provides for a federal/state social service grant-in-aid. The goals of the $2.5 billion dollar national grant are "to enable states to provide services directed towards self-support, self-sufficiency, protection of children and vulnerable adults from abuse, neglect or exploitation and strengthening family life and prevention of reduction of inappropriate institutionalized care by providing for community based, home based or other forms of less intensive care."[4]

In the past seven or eight years, there has been a growing national awareness of the need for community based, long term home care services for the aged, disabled and chronically ill; the functionally disabled. The 1981 White House Conference on Aging convened a special mini conference on long term care subtitled, "Strengthening Community Based, Long Term Care for Individuals."[5] Historically, community based, in-home health and personal care has received low national and state priority as reflected in the fact that in 1983, 90% of all, and 98% of public long term care monies

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[4] Warhola, C.R. Planning for Home Health Services: A Resource Handbook U.S. Department of Health & Human Services (H.R.A.) 80-14017: 51 p. 18.

[5] Final Report. White House Conference on Aging. Mini Conference on Long Term Care. 1980.

were paid to nursing homes caring for 5% of the disabled.[6] By contrast, in 1978, 1.8% of the total public health expenditures were paid for home health care.[7] In 1983, the combined total of Medicare and Medicaid monies allocated to home care was 3%. In summary, one could conclude that 3% of all public long term care monies was available for the 95% of the aged in the community who are potential consumers.

The nursing home scandals of the mid 1970s, soaring costs of nursing home care (an increase of 76.2% between 1976 and 1979)[8] combined with a six-fold increase in the absolute and proportionate number of people 65 years and over, since 1900, have begun to alter public sentiment and perhaps, over time, public policy. The virtual cessation of nursing home construction in New York State, the increased vigilance about the utilization of acute care hospitals as evidence in the DRG's, the Gray Panther Movement, an advocacy movement empowering healthy older people to organize and exercise political pressure, the recognition that older people and

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6 Vladeck, B. "Two Steps Forward, One Step Back: The Changing Agency of Long Term Care Reform. Pride Institute. Journal of Long Term Home Health Care 2, no.3, (Summer, 1983): 3-9, p. 3.

7 "Medicare Analysis and Recommendations for Reform." New York State Office for the Aging. September, 1983.

8 Final Report of the 1981 White House Conference on Aging. Vol. 1

their families prefer the home care option[9] contribute to Vladeck's perception that "home care must represent an alternative to institutional care and not the other way around."[10]

The scope of the issue is vast given that "homemaker, home health and home attendant services will be needed sometime in his/her life by every older person or by someone they know. It will be needed by individuals in all income brackets from the very rich to the very poor in every community across the nation."[11] The need transcends class and culture although ethnic differences do obtain, insofar as black older people require services at an earlier age than whites.[12]

As recently as 1981, Section 2176 of the Omnibus Reconciliation Act gave states flexibility to apply for waivers to fund a variety of home and community services

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9 Harris, L. and Associates, Aging in the Eighties: America in Transition. Washington, D.C.: National Council on Aging, 1981.

10 Vladeck, Ibid.

11 Winston, E. "Closing Institutions--Factors Behind the Gradual Shift in Social Attitudes." National Roundtable Conference of the American Public Welfare Association. New Orleans, Louisiana. December, 1974.

12 Engler, M. "The Impact of Ethnicity on Home Care Needs: A Comparison of Black and White Elderly." Presented at the 33rd Annual Scientific Meeting of the Gerontological Scientific Meeting of the Gerontological Society, November, 1980.

under Medicaid. As evidence of the appropriate national concern for home care, 40 states have applied for this waiver.

In terms of the current provision of service, New York State is the largest provider of Medicaid funded home care services in the nation. In fact, 80% of all national home health and personal care servicers are rendered in New York State programs with 73% rendered directly in New York City.[13] Between fiscal years 1982 and 1984, New York State expenses for Medicaid funded in-home care have nearly doubled: an increase from $300 million to $502 million.[14] In 1983, New York State was serving "over 50,000 clients...annual increases in expenditures have averaged 30% in the preceding four years."[15]

However great the cost of this public provision, recognition ought to be given to the fact that tens of thousands of jobs have been created for unskilled, poor women who elect to work.

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13 Crystal, S. Americans' Old Age Crisis. Lexington, MA: Lexington Books, 1982.

14 Caro, Ibid.

15 Planning for Home Care in New York State. 1983 Annual Seminar. New York State Council on Home Care Services. (September, 1983): 9.

DEMOGRAPHICS - THE GRAYING OF AMERICA

The population of people 65 and over is 25.5 million, representing 11% of the general population. A decrease in infant mortality, an increase in life expectancy and improved medical technology have been the major contributors to the "Graying of America." Future projections, "social indicators"[16] suggest that by the year 2030, 59 million Americans will be over 65. A number so vast requires further differentiation in order to determine the specific needs, now and in the future, of the group labeled "aged." Of the current 25.5 million aged, 9.9 million are 75 years and over, with two million 85 and older. Within the next 15 years, the "frail" population, 75 and over, is expected to increase by 64%. Within the next 50 years, the number of persons aged 75 to 84 is projected to increase by 140%, while those 85 and older is expected to nearly triple.[17] Despite the current low priority afforded home care, demographics clearly demonstrate a growing population who are soon to be in need of services.

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[16] Fowles, J.K. "An Overview of Social Forecasting Procedures." American Institute of Planners. (July, 1976): 227-234.

[17] United States Bureau of the Census, Current Population Reports, Series P-60, No. 129. Money Incomes of Families and Persons in the United States, 1979. Washington, D.C. 1981.

The definition of "frail" can be elaborated to include those with some sort of functional disability. As Caro states, those who "do not care for themselves because they cannot."[18] Of the frail elderly, 66-75% live in the community.[19]

Moreover, "data from the Home Care Supplement of the 1979 National Health Interview Survey shows that only 10% of the functionally ill elderly with an informal support network use formal services, compared to 80% without an informal network."[20] In effect, people turn to the formal system of caregiving when family is not available or existent. We can infer that those who use services do so out of real need.

Economically, the aged are disproportionately represented in poverty. The 1976 Special Report of the Senate Committee on Aging estimates that 3.4 million elderly are impoverished.[21] Alternative calculations of the poverty

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18 Caro, F. "Measuring Attainment of Objectives in Non-Institutional Long Term Care", presented at the 1982 Annual Scientific Meeting of the Geriatric Society of America.

19 Vladeck, Ibid.

20 Bass, D. and Voelker. "The Influence of Family Caregivers on Elders' Use of In-Home Services: An Expanded Conceptual Framework." Journal of Health and Social Behavior 28, (March, 1987): 184-196, p. 185.

21 United States Congress, Senate Special Committee on Aging. Subcommittee on Long Term Care. Nursing Home Care in the United States: Failure in Public Policy. 94th Congress, 2nd session, 1976. Committee Report.

index, including the "hidden poor" and near poor would raise the poverty figures by 38-39% of the aged population. The 1980 Bureau of the Census finds that 15-17% of the elderly had incomes below the federally established poverty line and 26% of the elderly are exceedingly close to the poverty level.[22] In 1980, 41% of aged women and 15% of the men were living in single households.[23] Of the seven million elderly living alone, 80% are women. Combining the facts of living arrangements with the incidence of poverty, one finds that three-fifths of the poor elderly live alone, suggesting that the multi-problem frail older population is indeed a particularly vulnerable segment of the aged population.[24]

The changing composition and mobility of the nuclear family in concert with the revolutionary impact of the estimated 57%[25] of women in the work force adds to the scope and significance of how and what society will provide for the functionally disabled who live in the community.

Although demographic, social and economic factors indicate a current number of frail older people to be in need

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22 United States Bureau of the Census, Current Population Reports. Ibid.

23 Crystal, 21.

24 Crystal, Ibid., 32.

25 Crystal, Ibid, 37.

of home care services, 1977 estimates indicate that only 12-15% of those in need of services are receiving them.[26, 27] The gap between need and provision can be accounted for by the discrepancy in the definition of home care services. While Medicare and Medicaid are home care coverages currently defined as an exclusively medical provision, the leading policy analysts in the field, Lowy,[28] Somers and Somers,[29] Crystal,[30] Caro,[31] Winston,[32] and Mundinger,[33] are in agreement that an alternative expanded definition of home care ought to include the psycho-social needs of the functionally disabled. Mundinger states that "2.3 million need (home care) services, and do not have them because of inadequate availability and restrictive eligibility."[34] While a social health definition of home care is consistent with the needs of the disabled population and the values of

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26 Warhola, Ibid.

27 Mundinger, Ibid.

28 Lowy, L. "Social Policies and Programs on Aging" in Markson, E.W. and Bakra, A. (Eds.) Public Policy For an Aging Society. Lexington, MA: Lexington Books, 1980.

29 Somers, J. & Somers, A. Health and Health Care: Policies and Perspectives. Gaithersberg, MD: Aspen Press, 1977.

30 Crystal, Ibid.

31 Caro, F. "Professional Roles in the Maintenance of the Disabled Elderly in the Community: A Forecast", The Gerontologist 14, no. 4 (August, 1974: 286-289.

32 Winston, E., Ibid.

33 Mundinger, Ibid.

34 Ibid., 14

social work, and while it may be a goal toward which we work, program planners need to attend to improving deficits in what is currently provided, as well as working on what should be.

THE FAMILY AS INFORMAL CARE GIVER

The myth that the American family has abandoned its older relatives is just that -- a myth. Not only is there relative ignorance of the documented fact that 80% of all care to the aged is rendered by family members[35] but recently there have been discussions around reinstating economic filial responsibility, a regressive attempt to lessen the role of government while increasing the burdens to already burdened care givers. The "current federal policy does not explicitly acknowledge the contribution of the informal systems."[36] According to the General Accounting Office, most families caring for an aging relative do not receive public, financial or service incentives.[37]

Caro has suggested that a primary purpose of home care ought to be to offset the burdens that the caregiving

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[35] Shanas, E. "The Family as a Social Support System in Old Age," The Gerontologist 23, (1983): 169-174.

[36] Final Report on the While House Conference on Aging, Ibid.

[37] General Accounting Office. "Entering a Nursing Home: Costly Implications for Medicaid and the Elderly." Report PAD 80-12, November, 1979.

family experiences. A number of studies[38, 39, 40, 41] report stress related illness, job interruption, depression, fatigue, fears, and guilt because of conflicting demands on time and marital discord. The potential breakdown of the informal support systems ought not be minimized. The impact on working class families is even more severe than on middle class families as options are more limited.[42] In essence, not only is the emotional cost to the middle aged care giver unrecognized, but suggestions have been made to increase the economic costs to families as well. There is currently no provision to acknowledge the economic value of family contribution to care. The real contribution of families is neither formally recognized nor publicly supported despite the American value of family cohesion and the original purpose of homemaking service, which was to provide services during times of crises to stabilize and maintain the family unit.

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38 Horowitz, A. "The Impact of Care Giving to the Chronically Ill Aged." D.S.W. Dissertation, Columbia University, 1981.

39 Archbold, P.G. "An Analysis of Parent Caring on Women," Home Health Care Services Quarterly 3, no. 2 (Summer 1982): 5-25.

40 Lebwotz, B. "Family Care Giving in Old Age," Hospital and Community Psychiatry 36, no. 2 (May 1985): 457-458.

41 Stoller, E. "Elder Care Givers' Relationship in Shared Households." Research on Aging 2 (June 1985): 175-193.

42 Archbold, Ibid.

Lowy suggests that we should be using the formal support system "buttressing options and supports that would strengthen its (the family's) capacity to meet the social, emotional and physical demands placed on it by ... the lack of knowledge on the part of the public about gaining access to adequate care."[43] There appears to be a fear that "expansion or provision of federal support to community based services will substitute for the informal[44] care giving. This, despite documentation that when formal supports are substituted for the absence or inadequacy of informal supports, nursing home placements can be delayed or averted altogether. The lack of policy to alleviate or support the family's role in care giving is only too reminiscent of the harsh conditions existing under Poor Law Regulations. The assumption that an increase in public provision yields a decrease in private contributions is refuted by the fact that the informal system seeks help from the formal system only after its resources have been depleted.

Alternatives have been proposed, yet await public exposure and sanction. In the mid 1970's, Representative Wilbur Mills suggested altering the tax structure to allow families a medical deduction for economic contributions made on behalf of aged family members.

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43 Lowy, 102.

44 White House Conference, Ibid.

Dr. Eugene Litwak has delineated two separate functions of care giving: the informal - that rendered by family in the form of emotional and support services, and the formal -that rendered by paid employees, which is primarily concerned with chores and tasks. This paper will focus on the issues surrounding the needs of the formal care providers, the home care workers.

In summary, community based long-term care services to the functionally disabled impacts on the three domains defined by Gil.[45] It is clear that the "quality of life, circumstances of living" and "relationships" cannot be separated. It is also clear that if one were to combine the numbers of people receiving services, those currently in need of services, those anticipated to become in need of services, and the families of those people with the needs of the home care work force, the scope of the issue becomes vast.

THE PROVISION: MEDICARE

The issue of what is being provided relates to what is believed about the cause of the difficulty. Since, by definition, home health care is targeted to illness, treatment or recuperation from medical conditions, preponderantly

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45 Gil, D. Unraveling Social Policy. Rochester, VT: Schenkman Publishing Co., 1976.

cancer, diabetes, and cardio-vascular disease,[46] the formula "nursing plus one" (the need for a nurse plus either occupational, physical therapy, or home health health aide service) provides for a nursing assessment to be made in the patient's home. There are three conditions to be met under the existing Medicare assessment for home care. The beneficiary must be: homebound, have services prescribed by a physician, and need part-time or intermediate skilled nursing service and one additional service such as physical therapy, speech therapy or home health aide services. Once approval is granted, a home health aide is assigned to provide personal care services limited to a 40 hour total maximum number of hours, with an average provision of four hours two or three days a week.

The acute care focus of Medicare home health service does not recognize that the elderly, as a group, require ongoing service rather than episodic ones to monitor conditions which may vacillate between acute and chronic.[47] The current policy, and therefore provision, restricts care to prevention or treatment of injury. Alternative understanding of the problem has been offered. According to the

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[46] Calvin, B. & Nelson, K. Home Care in New York State: A Descriptive Analysis. Home Care Association of New York, May, 1979.

[47] Furukawa, C. & Shoemaker, D. Community Health Services for the Aged: Promotion and Maintenance. Gaithersburg, MD: Aspen Publishing Co., 1982.

Health Service Agency, and corroborated by the Home Care Association of New York State: "functional status has been shown to be the best determination of the need for home care and of the length of service."[48]

Mundinger's study[49] finds that the medical bias reflected in these criteria are an inaccurate reflection of the patient's conditions in over 40% of the cases. The intermittent criteria does not accurately reflect the chronic nature of conditions incurred by the functionally disabled. Moreover, intermittent services are in contrast to the empirically documented needs of the population served. The medical bias reflected in this provision is equally inconsistent with need. In fact, "the chronically ill and elderly have multiple medical diagnoses and the most recent acute crises may have no relationship to the need for home care."[50] Furthermore, home health services under Medicare guidelines preclude long-term care.

To better understand alternative eligibility criteria requires a definition of the purpose of home care. Caro has suggested that what is needed is a formulation which looks upon maintenance of the functionally disabled as an end

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48 Calvin & Nelson, Ibid., 9.

49 Mundinger, Ibid.

50 Somers and Somers, 3.

in itself. These maintenance objectives in long term care should be concerned with the quality and circumstances of living. A basic purpose of long-term home care is to "sustain life."[51]

Comparison of the conditions of eligibility under Medicare home health services with the needs and conditions of the functionally disabled aged present serious incongruity between eligibility and need. In part, this problem is a function of the definition of home care as a health care service rather than a social-health care provision. A medical solution is imposed on a variety of social problems and the personal and social care needs of the population are unacknowledged. Institutionalization remains the main option for those whose needs exceed the 40 hour provision.

THE PROVISION: MEDICAID

The eligibility criteria for Medicaid, the state administered categorical medical insurance for the poor, has also been influenced by the medical model. Since Medicaid is a state administered program, there is a great variance in the options each state elects to include in its Medicaid menu. Only nine states have "exercised the optional personal care services."[52] Somers & Somers recommend an agreement on

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[51] Caro, "Measuring Attainment." 14.

[52] Warhola, 19.

definition to include "personal and household tasks"[53] regardless of income limits. As with Medicare, a physician's prescription is needed, yet the criteria for "homebound" and the requirement of "skilled care" are not preconditions. As of 1981, in 16 states the elderly and disabled living in the community could not become eligible for Medicaid, no matter how great their medical or long-term care needs, unless their income was so low that they were eligible for public assistance.[54]

Medicaid, in those states that allow the personal care option, provides a home attendant to perform some personal care services. Although staffing will be discussed later in this chapter, suffice it to say that the home attendant is less well trained and has less job security than the home health aide affiliated with a certified home health care agency. The provision of home attendant services is determined by a variety of public accountability mechanisms that will be elaborated on later. While theoretically services of a home attendant are available to eligible clients 24 hours a day, seven days a week, in fact in New York State, 24 hour care is becoming a rarity. According to the United Hospital

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[53] Somers & Somers, Ibid.

[54] Crystal, Ibid.

Fund 17% of the cases are 24 hours, as of 1987.[55]

SOCIAL HEALTH

There is a plethora of empirical data to support the social health definition of home care. Kristen and Morris found that most home care needed is for supportive services.[56] Markson[57] found that 77% of those hospitalized could have remained home if personal supervision had been provided. Parenthetically, the lease important need of the studied population was for medical treatment. A 1976 study revealed that the unmet needs of the community dwelling elderly were, in ranked order: transportation, personal care, housekeeping, social contact, food shopping and food preparation.[58]

An expanded definition of home health services, to include a social health definition, would allow for an increasingly need-meeting service. The major policy writers in

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55 United Hospital Fund Report, Home Care in New York City: Providers, Payers and Clients (1987): 48.

56 Kristen, H. & Morris, R. "Alternatives to Institutional Care for the Elderly and Disabled." The Gerontologist 12, no. 2, (Summer, 1972): 139-142.

57 Markson, E.W. "The Elderly in the Community: Re-identifying Unmet Needs." Journal of Gerontology 28, no. 4, (October, 1973): 37.

58 North Shore Planning Council, Inc. "Unmet Needs of the Elderly in Health Service Area IV," Department of Health, Education and Welfare, Washington, D.C., (March 22, 1976): 47.

the field: Lowy,[59] Winston,[60] Crystal,[61] Caro,[62] et. al., are unanimous in their support of a definition to include the social health model of service. This would permit the provision of the variety of support services that have been documented as reflecting the needs of the functionally disabled. The existing medical model of home care does not recognize that "long term care is a social as well as medical problem."[63] Not surprisingly, the current definition precludes social work services as a reimbursable service.

An expanded definition would acknowledge that the functionally disabled ought be enabled to approximate as normal a life style as is possible and provide a more adequate solution to the problems of daily living. It would recognize that the functionally disabled are so not out of choice or defect and are entitled to services which maximize their independence rather than presuppose a recuperation that is often medically impossible. It would use functional status as the primary criteria for services. An alternative provision would use "services needed rather than medical

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59 Lowy, Ibid.

60 Winston, Ibid.

61 Crystal, Ibid.

62 Caro, Ibid.

63 Crystal, 102.

conditions"[64] as the criteria for the provision. Inherent in the social health definition would also be provisions to "relieve the unreasonable burdens associated with care giving" and "provide relief to the care giver so that participation does not exceed a reasonable level."[65]

The broadest alternative definition of home health services is home care as social care for persons with "self care deficits."[66] Included in this definition is a socio-cultural approach to care. This definition is supported by the Final Report of the White House Conference on Aging -- Mini Conference on Long Term Care. Long-term care represents a range of services that address health, social and personal care needs of individuals who, for one reason or another, have never developed or have lost some capacity for self care. Services may be continuous or intermittent, but it is generally presumed that they will be delivered for the long-term, that is, indefinitely to individuals who have demonstrated need, usually measured by some index of functional incapacity. The larger White House Conference defines long-term care as "supportive services needed by persons who have functional limitations resulting from or in conjunction with

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64 Mundinger, 100.

65 Caro, "Measuring Attainment," 9.

66 Ibid., 5

chronic illness or other conditions which make them frail or dependent.[67]

In summary, we see services based on a strictly medical model, using diagnostic differentials and/or means test criteria for services rather than being based on "attributed need or compensation."[68] This fact does not reveal a value that enhances independence. The current needs of the functionally disabled older person are inadequately met, the "residual"[69] conception of social welfare is maintained. "No matter how benign the operational mechanism for eligibility determination, it is probably that the condition of unmet need will be attributed more to chance and individual deficiency than to recurring institutional strains or failures."[70] Given the demographics and the psycho-social-biological fact of aging "attributed need and compensation" ought to be the basis of social allocation to allow an "adequate institutional core of social welfare to emerge."[71] At present, Medicare, as a form of social insurance for the

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[67] Final Report on the White House Conference, Ibid., 71.

[68] Gilbert, N. & Specht, H. Dimensions of Social Welfare Policy. New York: Prentice-Hall, 1977.

[69] Wilensky, H. and Lebeaux, C. Industrial Society and Social Welfare, New York: Free Press, 1965.

[70] Gilbert & Specht, Ibid., 59.

[71] Ibid., 60.

functionally disabled older person, is an inadequate protection available under inappropriate criteria. Medicaid requires that in addition to functional disability, the condition for home care service is pauperization.

THE SERVICE DELIVERY MECHANISM AND ADMINISTRATION

Medicare Sponsored Home Health Aide Service

Medicare is a dual structure system with two separate insurance programs: part A, which is universal and mandatory, like social security, and part B, a voluntary supplementary medical benefit. The Social Security Administration's Bureau of Health Insurance is responsible for the program's administration. Within the Bureau, a variety of divisions exist, each responsible for overseeing operations, reimbursement and systems management. At its inception, of the 19 million people eligible for benefits, 92% elected to be covered under part B. The effort to avail beneficiaries to Medicare coverage can be seen as one of the largest, well coordinated and effective undertakings of the federal government. Recipients of Social Security were contacted en masse, by mail, using other agencies to do follow-up.

In addition to the federal structure, most of the daily operations of the administration of medicare are subcontracted to intermediary agencies, with Blue Cross and Blue Shield, the largest private insurance agency, serving as the

primary intermediary (90%). In the early 1960's, the American Medical Association nominated Blue Cross to assume this role. Further endorsement came from the American Hospital Association. Given the influential role of these two institutions in determining policy, it is reasonable to infer that ample profits provided incentive to this organizational arrangement among distributors.[72]

The intermediary functions as the federal government's representative to the local home health care agencies and is empowered to determine sanctions through a highly regulated system of audits. Eligibility for Medicare reimbursable home health care service is determined almost exclusively by the physical condition of the beneficiary, as prescribed by a physician and corroborated, through documentation, by a nurse. As a way of assuring adherence to regulations, once a 2.5% ineligibility waiver has been exceeded (the allowable error rate), "the agency must pay for all the ineligible care incurred that year" and, as further protection against excessive usage of what is deemed inappropriate usage, "the waiver is denied for succeeding years."[73] This rigorous cost control measure creates a dilemma between

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[72] Oatman, D. Medical Care in the United States. Jackson, TN: W. Wilson Co., 1978.

[73] Mundinger, Ibid., 67.

"bureaucratic discipline and professional expertise"[74] and ethics. The classical administrative dilemma between agency survival and client need obtains.

Reimbursement is operationalized through a claim payment system similar to private insurance operations. Structurally, the program -- from the national to the state level, and then the state to the individual level -- represents "neither a sudden nor a radical departure from the march of events in the organizing and financing of medical care and government's role in health...evolving over 30 years."[75] Local agency autonomy and control is limited by the intermediary which has economic sanctions that can be evoked under clear criteria. Informally, however, the professionals involved in the direct service delivery can, on occasion, manipulate their documentation to adhere to eligibility criteria.[76]

The primary service deliverer, in certified Home Health Agencies, is the Home Health Aide, considered one rung below a L.P.N. on the occupational ladder. She receives a

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[74] Blau, P. & Scott, W., "Dilemmas in Formal Organizations" in Etzioni, A. (Ed.) Readings on Modern Organizations. Englewood Cliffs, New Jersey: Prentice Hall, 1969.

[75] Bowen, W. Harbison, F., Lester, R. & Somers, H. The American System of Social Insurance: Its Philosophy, Impact and Future Development. The Princeton Symposium, 1967.

[76] Mundinger, Ibid.

specified number of hours of training, usually 72, and works under the supervision of an agency nurse. Unlike her counterpart in Medicaid home care, the home attendant, there can be more job security for a staff home health aide and somewhat greater financial reward. However, like the home attendant, the home health aide is without a career ladder.

MEDICAID

The structure of Medicaid is different from that of Medicare, yet administrative parallels exist. As was earlier stated, Medicaid is a federal/state financed program operated under the direct auspices of the locality. Each state determines its own eligibility requirements and benefit package, within federal guidelines. However, this determination of elected options is not always reflective of the needs of the citizens of any given state. Direct operation and accountability is shifted from the federal (and state) government onto an intermediary: a private insurance agency of the municipal government. Both systems are part of larger networks, serve middle management and regulatory functions and both are hierarchical. Both systems provide employment to many workers who perform the coordination and managerial functions associated with their tasks. (See organizational charts on following pages.)

HISTORY OF THE ECONOMICS OF HEALTH CARE EXPENDITURES

As with every other element of social welfare policy analysis, a study of the economic costs contains a variety of important issues. In addition to the value and choice dichotomies articulated by Gilbert and Specht, cost efficiency versus social control and local autonomy versus centralization,[77] cost analyses reveal that there is a history and structure that exert influence on disbursements and allocations. Furthermore, adequate analysis requires that costs be conceptualized in absolute dollars, costs relative to government allocations, within and beyond the realm of the health care system.

This part of the chapter will review the history of expenditures before and after the enactment of Medicaid and Medicare. It will analyze the current structure and process of the reimbursement system. Factors will provide support for the position advanced by Somers and Somers who wrote in 1966, "most of the pressures are not related to rational social goals, but to maximizing reimbursement."[78] Twenty years later, we come to see how an "obsession with economy" combined with short-sighted political consideration, grounded in philosophy concerned with maintenance of social economic class stratification continues.

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[77] Gilbert & Specht, Ibid.

[78] Somers & Somers, 126.

To understand the current costs requires an acknowledgement of the intent of Medicare. History makes it clear that the intent of Medicare legislation was not to overhaul the institutional structure of the health care system. Rather, the primary focus was to provide hospitals with insurance reimbursement and, secondly, to "provide the financial means for medical care for the aged"[79] to have greater access. The existing fee-for-service method of finance at the "reasonable costs" reimbursement did not provide for cost control. Rather, it allowed the profits of physicians, hospitals and nursing homes to soar. While Medicaid eligibility determination is rigorous, and for the most part conditional on pauperization, no similar profit levels are imposed on the income received by institutions. As Somers and Somers state, "in no other realm of economic life are payments guaranteed for costs that are neither controlled by competition nor regulated by public authority, and in which no incentive for economy can be discerned. This is a case where the existing method is almost certain to prove inappropriate and we must be prepared for the necessity of change."[80] In addition to lack of cost control incentives, Mundinger points to the fact that there is no incentive for the fiscal intermediary to be concerned with quality

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[79] Ibid., 127.

[80] Ibid. 134.

control either. In part, the dilemmas revolve around the ambivalence of seeing medical care entitlements as a genuine insurance or as a welfare program. It is, in part, the distinction between the residual or the institutional model of social welfare.

Prior to the enactment of Medicare, those with vested interests (Blue Cross, AHA, AMA) were arguing with "political muscle and bargaining skills" for a reimbursement mechanism that would be self-serving. A look at the figures reveals the consequences. Between 1960-1965, fee increases remained at 3%. In 1966, fees took an 8% jump. "Between 1966-1967, health care costs for the elderly rose 29%,or 190% in real dollars." Of note is that the administrative costs in 1967 were $197.3 million dollars, or 5 1/2% of the total costs -- a sizeable fee for Blue Cross.[81]

In 1976, The Committee on Aging of the United States Senate revealed that Medicaid has paid $5.3 billion dollars to 15,559 nursing homes. Medicaid payments represented 50% of all nursing home revenues in contrast to Medicare's $314 million, less than 2% of the $18 billion dollar Medicare program. Despite the ostensibly high cost of home care, evidence of the limited contribution of public monies for home health care unfolds. Medicare "expenditures for

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81 Ibid., 134.

home health service peaked in 1971 to 0.48% of total expenditures and had decreased by 1975 to 0.28% of the total. Medicare payments for home health care peaked in 1969 to 1.1% and had decreased in 1973 to 0.7%.[82]

Medicare spent about $133 million on home care in 1974. By 1980, the figure was $630 million, an increase of nearly five times. "Program data indicates that the use of Medicare Home Health Services grew from about 760,000 users in 1977 to approximately 1,340,000 users in 1983, an increase of nearly 77% for the period, or an annual rate of 10%...between 1977 and 1983 this amount grew by more than one billion dollars, i.e., expenditures nearly quadrupled to a total of 1.4 billion in 1983. Annually this represents an average of 25.4%%.[83] Warhola reports: "In 1977, a total of $1 billion was spent for home care. Medicare paid $458 million, Medicaid, $179 million and Title XX, $445 million."[84] Yet, this reflects less than 1% of the total public health care costs. The increase in absolute costs can be attributed to the outrageous increase in nursing home

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82 United States Congress, Senate Special Committee on Aging. Subcommittee on Long Term Care. Nursing Home Care in the United States: Failure in Public Policy. 94th Congress, 2nd Session, 1976. Committee Print.

83 Benjamin, A.E. "Trends and Issues in the Provision of Home Health Care: Local Governments in a Competitive Environment." Journal of Public Health Policy 7, no. 4, (1986): 480-494.

84 Warhola, 17.

costs which rose 76.2% between 1976 and 1979.[85] Clearly, attempts to reduce the cost of institutionalization motivated the increase in home care approval and usage.

By 1982, the average cost of nursing home care in New York City was $28,000. Nationally, "over half of the $20 billion spent in housing old people in nursing homes is publicly paid."[86] More specifically, 42% of the total Medicaid expenses went for nursing home care in 1978, rising to 57% the following year."[87] By contrast, only 2% of the total Medicare monies were paid to nursing homes. The implications of this are broad. To the public a surface reading of Medicaid costs could easily be understood as earmarking enormous sums of public monies for increased access to medical care of the poor. Yet, if 57% of public monies pay for some proportion of the 5% in nursing homes, access to the non-institutionalized poor is lessened. Otherwise stated, "16% of all enrollees represent 40% of Medicaid expenses."[88] By implication, an increased resentment to the aged for depriving other medically needy groups might be a consequence. A more sophisticated analysis might inquire about

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85 Crystal, 67.

86 Ibid., 67.

87 Ibid., 6.

88 Vladeck, 5.

the nature of a benefit allocations system which is designed to allow for this to occur.

To the extent to which government support for social welfare is reflected in expenditure of public funds, community based long term home care services for the aged, disabled and chronically ill - the functionally disabled - has been a relatively neglected group in social welfare policy. This group has received low priority. Despite uncontrolled inflation in nursing homes, "90% of all monies, and 90% of public long term care monies, were paid to nursing homes."[89] By contrast, in 1978 1.8% of the total Medicare expenditures were paid for home health care.[90] In 1983, the combined total of Medicare and Medicaid monies reimbursed for home care services was 30% of total public health insurance expenditures.[91] In summary, 3% of all public long-term care monies have been allocated for the 95% of the aged in the community who may need care, while 97% of public long-term care monies are paid to nursing homes who provide care for 5% of the aged population.

There are other costs not included in this economic formulation. There is currently no provision to accommodate

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89 Ibid.

90 Medicare Analysis and Recommendations for Reform. New York State Office for the Aging, September, 1983.

91 Ibid.

the economic value of family contribution to care. The General Accounting Office estimates that the value of services provided "by family and friends to extremely impaired persons was $673 per month in 1976-1977."[92]

The cost benefits of supporting family caregiving are less well addressed. Federal policy that subsidizes family care may avoid increases in public expenditures in the way in which greater, less cumbersome home care provision would lessen hospital costs. Since there is no explicit policy for chronic care, it follows that the acute care medical model is not only less effective, but less economical as well.

POLICY ALTERNATIVES

Alternative policies have been suggested. Crystal suggests that reimbursement to families could be structured as a tax credit and/or limited to families in financial need. This might encourage family caregiving while attending to those with less economic freedom. Monk suggests tax rebates and cash allotments could provide incentives. Seltzer and Troll support direct funnelling of money and resources to families who want to provide care..."[93] Kamerman and Chain appeal to tradition and ethics. "It is a deliberate attempt

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[92] Crystal, 79.

[93] Seltzer, M. & Troll, L. "Conflicting Public Attitudes Toward Filial Responsibility," Generations (Winter, 1982): 26.

to destroy the family when government programs pay for institutionalizing an elderly parent, but not for caring for that parent at home." They ask, "What does it suggest about the government's motives when there is an implicit recognition that if long term care is needed, a couple divorces or a spouse is pauperized in order to be eligible for Medicaid?"[94]

To the extent to which public opinion is an indication of future direction, Louis Harris finds that 90% of the people polled approved of a tax break to families that provide care at home for the elderly.[95] His study also revealed that 87% of those polled support an expansion of the present short-term and time limited home health benefit. While policy alternatives need to be explored to better meet the needs of the frail elderly and their families, at the moment we can just deal with what it is.

PART II - THE NEEDS OF HOME CARE CLIENTS

Services are developed based on needs. It is therefore relevant to review the existing literature on the needs of home care clients.

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94 Kamerman, S. & Kahn, A. "Explorations in Family Policy." Social Work (May, 1976): 181-186.

95 Harris, L. and Associates. Ibid.

As early as 1971, Morris and Katris estimated that of those aged in the state of Massachusetts in need of home support services, "...a mere 2.4% were receiving them."[96]

Based on a variety of empirical sources, it is clear that medical services are not the primary need. Kristin and Morris (1972) found that most supportive services needed by the elderly and disabled are non-medical and can be provided by relatively non-skilled personnel.[97]

Markson, in reviewing the patient records and interviewing 348 older people referred to a mental hospital, concluded that 77% of those hospitalized could have best had their needs met through community services. The study further revealed that the greatest need of a change in location was for personal supervision. Although 455 of the needs were for home health, the least important need was for medical treatment, expressed by 17% of the population studied.[98]

The rank ordered unmet needs of the elderly in Health Services Area VI of Massachusetts were reported in a

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[96] Morris, R. and Katris, E. "Home Health Services in Massachusetts," American Journal of Public Health 62, no. 8, (August, 1972): 1088-1093.

[97] Kristin, H. & Morris, R. "Alternatives to Institutional Care for the Elderly and Disabled." The Gerontologist 12, no. 2, (Summer, 1972): 139-142.

[98] Markson, E.W., "The Elderly in the Community Re-Identify Unmet Needs." Journal of Gerontology 28, no. 4, (October, 1973): 503-509.

study sponsored by the North Shore Health Planning Council. They are: "Transportation, personal care, housekeeping, social contact, food shopping, food preparation, emergency assistance and social interaction."[99] The finding of this study represents a direct parallel to those services rendered by Home Attendants. An interesting finding of this study is that in most categories, the chronically ill appear to have a greater prevalence of unmet needs than the elderly, suggesting support for the social health definition offered by Caro, et. al. Further implication is that need rather than age be the criteria for service. This is supported by evidence presented by Engler[100] on the differential needs of Black and White elderly.

A 1975 New York State demonstration project (Project #39) provided nursing, homemaker, home health aide and prescribed therapeutic services on an as needed basis to older persons not eligible under Medicare and not poor enough to qualify for Medicaid ("Medigap"). Procedures included professional assessment of need for each patient referred, creation of a plan, and team care emphasizing use of aides supervised by nurses as well as a periodic review of appropriateness for each cost. Data collected from November 1973

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99 North Shore Health Planning Council, Inc., Unmet Needs of the Elderly in Health Service Area IV. Washington, D.C., Department of Health, Education and Welfare, (March, 1976): 47.

100 Engler, M., 16.

through December 1974 show that of 518 referrals, 433 were in need of services. Findings indicate a substantial need for home care services in the Albany area, the ability of comprehensive home care to prevent or postpone institutionalization and the need to bring home care into the mainstream of health care delivery.[101]

A descriptive analysis of Home Care in New York State (1979) found that: "in general, many home health care agency patients had serious maintenance problems. Without help from home health care, friends or some other supportive service, most patients would not be able to remain at home." Further evidence from this survey reveals that of the clients served, 90% need household assistance and 75% need marketing, with most clients needing both. "The typical home health care episode lasted about six to seven weeks, yet some patients remained in care for very long periods, up to 6.5 years, indicating the long-term needs of the population.[102]

Warhola states that the number of persons who are potential users of home health services has been estimated to

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101 Project #39. An Expanded Concept of Home Health Care. Sponsor: Albany Regional Medical Program, New York Home Aid Service of Eastern New York, Inc. Albany, N.Y., V.N.S. Association of New York, (May 1975): 14.

102 Home Care in New York State: A Descriptive Analysis. Published by the Home Care Association of New York State, Inc. (May, 1979): 29.

be over 6 million, but in 1977 only 738,000 received services.[103]

In 1982, a twelve month longitudinal study conducted in six New York City hospitals (3 public and 3 voluntary) explored the impact of publicly funded home services on the at-risk, low income elderly population. Although the author addresses methodological difficulties, the results demonstrate that hospitals are "returning substantial numbers of elderly functionally disabled persons to home settings without services and without assurances that informal supports can adequately provide needed care." The results indicate a gap in service between discharge and the provision of adequate supports and services. By implication, hospitals appear to assume rather limited responsibility for post hospital care. Discharge plans had been arranged for only 40% of the 86% returning home. More troubling is that of those with the severest disability, only 54% had services in place and 63% of those who lived alone were discharged without services.[104] There is a restriction placed on hospital workers to offer home services when financing is anticipated to be problematic, highlighting the cogency of these issues.

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103 Warhola, Ibid., 5

104 Caro, F. "Post Hospital Care Arrangements for the Functionally Disabled Elderly." Presented at the 1982 Annual Scientific Meeting of the Gerontological Society of America.

The finding that the most severely ill and those who lived alone are being discharged without concrete supportive services presents serious issues of ethics and may be construed as malfeasance. It is important to note that the limitations of service options are imposed in part by the lack of availability of publicly funded alternatives.

Hinzpeter and Fischer conducted an exploratory study on Manhattan's West Side. One hundred at home interviews were conducted of people aged 70-97. The study found predominantly poor, disabled, needy and dependent people who, for the most part, lack the usual supports of family and friends. The subjects were in unexpectedly poor physical and mental health, and socially isolated, and do not have sufficient income to meet their needs. "Overall, the study found a great need for additional assistance with carrying out everyday chores and activities." Even greater was the need for basic necessities such as housing, companionship and money.[105] It appears on face validity that over time the needs of the functionally disabled elderly have intensified rather than relaxed. This is supported by Caro's finding

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105 Hinzpeter, D.A. & Fischer, J.H. "Graying in the Shadows: A Study of Manhattan's West Side." Human Services 3, no. 13 (December 1983): 21-32.

that between 1980 and 1982, the number of home care requests has risen by 11%.[106]

In assessing the home care needs of the elderly, it is important to address issues of ethnicity insofar as "53% of the Black elderly are in or near poverty."[107] Engler's comparative study of the differences between Black and White elderly using home care services in New York City offers some painful conclusions, reflective of the impact of the historic inequities of racism on the Black elderly.

She studied 322 clients (65 years and over) receiving Title IIIB in home care program services. "Although the findings indicate substantial proportions of white elderly share characteristics on age, income, children, and availability of a doctor, there are statistically significant differences between the Black and white samples."[108] Black recipients are younger (mean age, 70.8 versus 77%), poorer (52.1 versus 31.9%), incomes at or below Medicaid level, had fewer living children, limited access to physicians (20.5 versus 3.6%). Blacks are more likely to be hospitalized in municipal hospitals (29.4 versus 9%). More than 40% of this sample in need of home care services was under 75 years of

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106 Caro, F., "Structure and Operation," Ibid.

107 Crystal, 36.

108 Engler, 4-5.

age, suggesting that for the Black elderly and probably all disabled, need rather than age ought to be the determinant of services. This position is supported by Caro who states that while his "current formulation uses functional disability as a basis for establishing need for long-term care, it does not use functional disability as an outcome variable for long-term, care."[109] Furthermore, "it must be understood that a basic purpose of long term care is to sustain life."[110]

HOME CARE PROGRAMS, THE HOME ATTENDANTS AND THE HOME HEALTH AIDE

Home Care Programs are reviewed to detail the ways in which they are need-meeting or define service gaps. The survey of the workers combines Home Attendants, Homemakers and Home Health Aides since, with the exception of Dr. Donovan's study, there was a relative lack of attention given to the Home Attendant as a discrete occupational entity. Despite the discrepancy between the scope of needs and available public funding, it is relevant to review the empirical data available on those programs currently in operation.

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109 Caro, F. "Objective Standards and Evaluation in Long-Term Care." Home Health Care Services Quarterly 12, no. 1 (Spring, 1981): 11.

110 Caro, F. "Measuring Attainment of Objectives in Non-Institutional Long-Term Care," presented at the 1982 Annual Scientific Meeting of the Gerontological Society of America.

The problems of a Title XX Home Care Service Program uncovered in a 1977 study by Friedman, Kay and Fargo include: inefficient payroll system, lack of adequate case management and supervisory mechanism. Poor match between client and worker, lack of preparation of client and family, inoperative emergency procedures and scarcity of worker training programs.[111]

Washington University sponsored a study in 1978 which revealed the problems confronting the long-term care system for the elderly in Washington state. These include a lack of emphasis on ongoing maintenance and support, lack of a service continuum, neglect of the near poor clients, requirements for spending down resources, stigmatizing by association with welfare clients, lack of comprehensive assessment and placement procedures, inadequate training and/or inexperienced providers, difficulty in reimbursement of expenses, lack of evaluation data and lack of explicit policies on long term care.[112]

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111 Friedman, S., Kaye, L. and Fargo, S. "Maximizing the Quality of Home Care Services for the Elderly," presented at the 30th Annual Scientific Meeting of the Gerontological Society. November 21, 1977.

112 "Long-Term Care for the Elderly in Washington." Sponsor: Washington University, Seattle, Washington, Health Policy Analysis Program, 1978.

Caro's interviews with administrators and workers in New York City's home care system summarized reported difficulties and barriers in services. These include: establishing Medicaid eligibility, providing sufficient documentation and processing of applications. Appropriate number of hours - "the number of hours of care authorized by the medical review units (the gate keepers) is often less than the number recommended by the case managers." When the home care client lives with a family, the burden of proof of need remains with the family. However, fair hearing, the legal due process mechanism for appeal, often results in overturning a denial of service. This suggests that given the arbitrary nature of these decisions, those clients and their families who can persevere and advocate are more likely to be successful. Since home attendants are not paid for travel time and represent entry level positions, it is often difficult to find workers willing to assume part-time assignments. Clients and workers may have differing expectations, cultures and may not share language.

Home attendants are to provide personal care, not health care. Yet, health care has been informally performed, rendering agencies liable for suit. Twenty-four hour cases pose problems in terms of sleeping arrangements and sharing food. Retrieving reimbursement from "spend down" Medicaid clients is costly and problematic, as well. Home care workers are vulnerable to abuse. Caro notes that problematic

areas have been omitted by his reporters which include: (1) denial of service; (2) Medicaid ineligibility; (3) cost control precludes "intensive supervision; and (4) services are done by "entry level" workers.[113]

A summary of these findings can be categorized into three areas: administrative (payroll, reimbursement), policy (eligibility restrictions and gaps), client and worker expectation. The most thematic areas of difficulty appear to be concentrated on the experience, training and performance of the homemakers/home health aides/home attendants.

To the extent to which in-home services are provided, the primary direct provider is the homemaker/home health aide/home attendant (H/HHA/HA). The issues of human resource needs, training, status, attrition and supervision of the home attendant are directly relevant to the formulation of the current study.

In 1963, 3,900 people were employed by home care agencies throughout the country. That number has soared, along with in-home service needs, to some 240,000 full-time workers. They are viewed by Moore and Layzer as somewhere between domestics and nurses and function to "help families to remain together, and elderly persons to remain in their

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113 Caro, "Structure and Operation." Ibid.

own homes when a health and/or social problem occurs..." "The trained home health aide...works under the supervision of a professional person.[114] Training is a federal requirement under Medicare and Medicaid conditions of participation. Yet the actual training mandated for home attendants is a total of 6 hours a year of in-service training.

Phillips refers to the home attendant as a family health worker and views this as a "new profession whose training uniquely prepares him/her to help solve the problems faced by the elderly." The worker is trained in health and psycho-social understanding of older people and operates along the dual paths of nurses and social workers.[115]

Steeno et. al. perceive the homemaker as a social service professional and a primary change agent and suggests that homemaker service be elevated to equal status with other professional service providers.[116]

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114 Moore, F.M. and Layzer, "Supporting the Homemaker/Home Health Aide as a Valuable Player on the Home Care Team." Pride Institute, Journal of Long Term Home Health Care 2, no. 3 (1983): 19-27.

115 Phillips, A.K. "Health Services to the Elderly--Family Health Worker--A New Profession." National Technical Information Service, (September, 1975).

116 Steeno, T., Moorehead, B.B., and Smith, J.R., "Homemakers as Change Agents," Social Casework 58, no. 5.(1977): 286-293.

HOME ATTENDANTS, HOMEMAKERS, HOME HEALTH AIDES; STATUS/TRAINING AND ATTRITION

The Health Planning Agency of Southern New Jersey collected baseline data to determine manpower deficiencies in health related occupations. The only projected areas of growth indicated by public health agencies is for sanitary inspectors, nurses and home health aides.[117] This growing need for in-home service is echoed by Clark.[118] Winston estimates that one aide is needed for every 100 persons over 65 and anticipates a need for 200,000 home health aides.[119]

In contrast to the professionalization of home care workers suggested by others, Caro sees the needs of the functionally disabled as primarily requiring personal care and home maintenance service which can be provided by non-professionals.[120]

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117 Comprehensive Health Planning Agency of Southern New Jersey. Health Manpower in Southern New Jersey. Public Health Service, Rockville, MD, (1976): 34.

118 Clark, M.M. "Returning Home---A View of the Home Services Field." National Council of Homemaker/Home Health Aide Services. (April, 1977).

119 Winston, E., Ibid.

120 Caro, F. "Professional Roles in the Maintenance of the Disabled in the Community: A Forecast." Gerontologist 4, no. 14 (August, 1974): 286-289.

Allied with the issue of status and perception of the role of the home health aide is the nature of the training. In 1966 the Office of Economic Opportunity (O.E.O.) and the Public Health Services (P.H.S.) recommended that the responsibility for training should be assumed by the agency that will eventually employ the aide.[121]

A 1975 study was conducted to delineate the medical and health related needs of nursing home residents. One recommendation of the Maricapa County Comprehensive Health Planning Council was the introduction of special training courses and career incentives to nurses aides.[122]

In 1978 questionnaires were sent to 175 institutions employing aides. This project was undertaken in Michigan to study institutions which provide nurses aides and home health aides trained in hospitals, nursing homes and schools. Hospitals supplied the least number of trained aides while nursing homes the greatest number of trained aides. This lack of a common or agreed upon model for aide training is noted. There is great variation on length of training and frequency of offerings. The problems which emerged from this

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121 Guidelines for Home Health Aide Pilot Training Projects. C.A.P./O.E.O., Washington, D.C., March, 1966.

122 Study of Nursing Homes in Maricapa County. Sponsor: Comprehensive Health Planning Council of Maricapa County, Phoenix, Arizona, (August, 1975): 118.

study were the lack of career mobility, high turnover rate, duplicative education and training, and dead end jobs.[123]

Regardless of training or status, the problems associated with the aide's job are multiple. A yearly attrition rate of from 38 to 52% for aides trained by the Home Attendant Service of Eastern New York prompted a study to determine the reasons for termination of employment. A 1975 survey was taken of a random sample of twenty entry level aides who had completed two weeks of training and had terminated their employment after an average of ten months. These results were compared with those from a similar survey of aides still employed after at least 31 months. Both terminated and continuing aides reported dissatisfaction with salary levels. Evidence of an inadequate formal system of rewarding excellence in performance was presented. College graduates were identified as a relatively high risk attrition group. Job-expectation appears to have been a relevant variable. Aides who continued working had an accurate expectation of their job duties at the time of hiring. Job satisfaction factors apparently do not play a specific role in employee attrition. Following implementation of recommended salary adjustments and a system of job performance feedback,

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123 Staff Report Nurses Aide/Home Health Aide Study. Sponsor: West Michigan Health System Agency, Grand Rapids, Michigan, (1978): 12.

another study will be conducted with those in facilities with lower attrition rates.[124]

Consistent with the finding cited above, a study of recruitment and attrition of homemaker/home health aides found that low pay, along with associated problems of poor fringe benefits and insecure incomes remains the central issue in attrition problems. Agency size, salary and benefit packages were found to be the most significant factors influencing retention of homemaker/home health aides.[125]

Combining the issue of status and participation, a 1975 evaluation of the impact on team nursing was implemented in rural Maine. Five semi-autonomous teams (home health aides, homemakers, registered nurses and therapists, as needed), directed by a nurse, showed that more cost-effective staffing was possible and in-service education time expanded.[126]

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124 "Employment Attrition Factors Among Home Health Aides of the Home Care Service of Eastern New York." Sponsor: Albany Regional Medical Program, New York, (March, 1975): 48.

125 United Commission Planning Corporation of Boston. A Study of Recruitment and Attrition on Homemakers/Home Health Aides, Boston. UCPC. 1975.

126 "Evaluation of the Impact of Team Nursing on Health Services Administration and Delivery in a Home Health Agency." Sponsor: Medical Care Development, Inc., Augusta, Maine. Bureau of Health Resources Development, Rockwell, MD (May, 1975): 14.

In 1977 Beasley conducted an exploratory study on job satisfaction with job preparation and with the job itself as perceived by homemakers employed in a Denver Department of Social Services. Personnel interviews with 12 homemakers elicited a response pattern that found satisfaction with the job, not with chore services, a desire for more input in planning for in-service training, more autonomy and more respect for their opinions from case workers.[127]

The object of an experimental project conducted between 1976 and 1980 in Finland was to study the effects of a few homemakers, employees of social welfare boards, spending longer periods of the day working with at-risk families. The homemakers, working under the professional supervision of psychologists and social workers, would have regular team meetings to clarify objectives and develop treatment plans. The results indicate that the prestige of homemakers was enhanced, their skills and professional status extended. As a consequence, "basic and supplementary training for homemakers is being increased to fit homemakers for a

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[127] Beasley, J.T. "Satisfaction with Training and General Satisfaction of Agency Homemakers Working With the Elderly and Disabled." Ph.D. dissertation. University of Denver, 1977.

more supportive and educative role in relation to their clients."[128]

Quality

There have been few empirical studies conducted to determine the quality and quantity of homemaker/home health aide services. In an exploratory study by Fashimpar and Grinnell, conducted in a Visiting Nurse agency, 143 questionnaires were sent to recipients of Home Care Services. The three main objectives achieved for clients were decreased feelings of isolation, prevention of nursing home entry and help getting into nursing homes. Homemaker/home health aides are perceived to be very effective in improving the quality of life and quantity of home care for their clients. Improved home care means that clients are left alone less of the time and receive meals with greater regularity. Clients perceive homemaker/home health aides as having many roles. Simultaneously, they are viewed more as professionals than servants. The professional roles correlate highly with adequacy of client service. The authors suggest that future research should focus on the homemaker/home health aides specifically: job description, job satisfaction/

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[128] Majuri, R. "An Experiment on Planned Long-Term Family Casework, Using Homemakers Supervised by Experts." Presented at the Sixth International Congress of Home Help Services. May, 1981. Stockholm, Finland.

dissatisfaction and objectives.[129] Implied in this study is the fact that the homemaker/home health aide combines both social welfare and health oriented functions.

In a follow-up study Fashimpar presented the results of a project which tested a management tool for evaluating the adequacy and quality of homemaker/home health aide programs. The Homemaker/Home Health Aide Program Evaluation Questionnaire (H/HHA-PEQ) is a self-report questionnaire. A sample drawn from the client population of the United Neighborhood Association of Dallas filled out the questionnaire. Using a test-retest method, results indicate that H/HHA-PEQ is a "content valid and reliable self-report questionnaire with an average correlation of all items of $r = .81 = 129$."[130]

There is controversy in the literature around upgrading the status of the aide (Major, Layzer, Philips and Steeno) or acknowledging the work as non-professional (Caro, Kristen and Morrios). Reflected throughout is the need for economic incentives, recognition, and participation by the aide with other people involved in client care. The authors'

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129 Fashimpar, G.A. and Grinnell, K.M. "The Effectiveness of the Homemaker/Home Health Aide." Health and Social Work 3, no. 1 (February 1978): 147-165.

130 Fashimpar, G. "A Management Tool for Evaluating the Adequacy and Quality of Homemaker/Home Health Aide Programs." The Gerontologist 23, no. 2, (1983): 127-131.

experience in hiring home attendants and later on training them, reveals that as a group, they are predominantly poor, minority, recent immigres, women who are single parents living in the inner city. They walk the tightrope between being independent workers or women dependent on public assistance. To the extent to which home care services can meet the criteria of quality care, further research ought explore the demographic and concrete needs of this work force.

The first study to address the Home Attendant directly, was conducted by Dr. Rebecca Donovan of Hunter College School of Social Work. Four hundred and four randomly selected unionized HA's working in New York City Home Attendant Programs were interviewed in 1985. A summary of findings indicates that: 99% of the participants are females with an average age of 47, 36% are married while 64% are unmarried, 36% are high school graduates, 70% are Black and 26% Hispanic. Forty-six percent are foreign born and preponderantly from the Caribbean, 85% have children (3.5 on the average), 76% of the workers are primary breadwinners. The most frequently reported salary was less than $5,000 annually. The median total family income reported was $8,000, as such 80% are not able to afford adequate housing, 69% are unable to afford adequate furniture and 35% reported that they often do not have enough food for their family. Thirty-three percent reported an inability to afford needed medical care. "Nearly all (85%) reported difficulty in meeting the

monthly family bills, with 62% reporting they simply do not have enough money to make ends meet."[131, 132]

The vast majority of the home care workforce is comprised of women of color who are the head of household. Donovan, in her paper "Home Care Work: A Legacy of Slavery in United States Health Care", provides a concise historic review tracing the role of Black women during slavery, than as freed slaves where "labor market opportunities remained virtually unchanged...through to 1940 when 70% of all Black working women found employment in private household service. Essentially the "industrial economy of the early twentieth century virtually excluded Black workers."[133] While legislation of the 1960's increased access to other arenas of employment, "shifts in employment since 1960 have involved the creation of occupational 'ghettos' within the lowest paying and least desirable segment of the typically female occupational categories.[134]

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131 Donovan, R. "The Health and Social Need of Home Care Workers." Preliminary Report: Summary of Survey Findings, 1985, TMs.

132 Donovan, R. "Stress in the Workplace: A Framework for Research and Practice." Social Casework 5. (May, 1987): 252-272.

133 Donovan, R. "Home Care Work" A Legacy of Slavery in U.S. Health Care." AFFILIA: (Fall, 1987): 33-39.

134 Ibid, 39.

As was indicated earlier in this review, one of the motivating forces for the expansion of the Home Care Industry was grounded in the perception that community based care offered a more cost efficient method of service delivery and provision.

> To quote Donovan: "Wage scales are kept low and fringe benefits are either severely restricted or not provided. Thus, health care costs are being reduced via the exploitation of a large cadre of minority women workers. This system promotes job insecurity that, along with the lack of opportunity for advancement, maintains poverty-level wages and benefits in the non-professional sector of the home care industry.[135]

The poverty level or near-poverty level wages of these working women, while understood as occupational segregation, grounded in an economic incentive to the government, perpetuates racism and sex discrimination while negatively impacting on the children being raised in these working poor families. While it is beyond the scope of this study to explore the impact of such poverty on the children of HA's, it is likely that the children of these workers may be deprived nutritionally, educationally, recreationally and in their general quality of life. Will they too inherit a "legacy of slavery"?

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135 Ibid., 35.

RECRUITMENT

Not sufficiently addressed in the literature on Home Care Workers is the issue of recruitment. A 1979 demonstration project was conducted in Georgia to train and employ voluntary participants from A.F.D.C. The hope was that the employment needs of a dependent population could be met while allowing social and health agencies to expand existing services.[136] There appears to be a growing trend to hire former public assistance recipients.

Between 1977-1979, this author was engaged in training Public Assistance recipients who were seeking employment as Home Health Aides. Experience revealed that of those trainees involved in a project co-sponsored by the Visiting Nurse Service of New York City and the New York City Department of Social Services, a large number of participants were in need of the spectrum of social work interventions. Given the increased attention to long-term in-home care, and the projected need for an expanded labor force, further research is needed to clarify and document the needs of Home Care Workers as well as explore the structural changes in the industry itself. To paraphrase Donovan, attention must be paid not only to the needs and troubles of workers but to

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[136] Home Health Aide Demonstration Project: A Report top the Commissioner." Sponsor: Friends of the Earth. Melbourne, Australia, (1979).

"the troubling working conditions" which these women experience.[137]

Elliot Sklar, a noted economist, states "the economics of the situation are such that these services must be provided by a low wage work force. This creates a situation where those workers considered most marginal to the economy provide a service to those people considered most marginal to society.[138]

The next chapter will describe the methodology used to conduct the study.

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137 Donovan, R. "Stress in the Workplace," 259.

138 Sklar, E. in Public Policy for an Aging Population. Markson, E.W. & Bakra, A. (Eds.), Lexington Books, 1980.

CHAPTER III - METHODOLOGY

INTRODUCTION

This chapter will describe the research design, target population, sample selection and data collection instrument used for this study. The last part of the chapter will discuss the strengths and limitations of the methodology.

In the way in which social work looks at the person in the environment, so too this research project needs to describe the interorganizational and interpersonal processes which allowed this study to occur.

This chapter will begin with a brief history of the evolution of the study.

PART I - HISTORIC/CONTEXTUAL DEVELOPMENT OF THE PROJECT METHODOLOGY

A computerized literature search based on the subject: Publicly Funded, Community Based Long-Term Home Care of the Frail, Infirm Elderly revealed several important findings. In particular, as of 1983, 80% of all Medicaid funded in-home care in the nation was rendered in New York State, and 73% of those services were rendered directly in New York City.[1] In absolute numbers, some 40,000 home care clients were receiving services from approximately 45,000 - 50,000 home care workers.[2] One of the authors writing in the home care field suggested that "studies might focus on the needs of the home attendant herself."[3] Another finding was the virtual absence of literature about this growing occupational cohort.

Concurrently, this author was involved in a New York State funded training effort to enhance the knowledge, skills and attitudes of personnel specialists and home care nurses; i.e., the middle management staff of Home Attendant Programs. This staff is responsible for hiring, orientation, job assignments and in-service training of home attendants (HA) working in New York City vendorized Home Attendant Programs (HAP). Information gathered from training over 200

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1 Crystal, S., Ibid.

2 Caro, F. "The Structure and Operation," Ibid.

3 Fashimper, G. "A Management Tool," 131.

personnel specialists and home care nurses confirmed that the needs of HA's were great but that no formal vehicle for provision of service to them existed. It became apparent that the specialists had two case loads: the designated clients and the HA's themselves. It also was apparent that while HA's had multiple needs and difficulties, the structure and mission of the agency precluded intervention on behalf of HA's.

These facts, combined with the direct practice experience of the author, who had worked in a Home Attendant Pilot project in 1971, led to the realization that little was known about a growing population of community based health care workers. It was believed that this cohort was comprised of minority and/or immigrant women, many of whom were the head of their household, who lacked adequate income, career ladders and fringe benefits. These were women who could benefit from social work intervention as well as from better pay, improved working conditions and increased fringe benefits.

This formulation of the worker-as-client propelled further inquiry with various executives of HAP's and the City's Home Care Service Program which oversees contracts with vendor providers. Since Medicaid is a federal and state partnership, New York State funnels federal Title XIX Medicaid monies through the Human Resource Administration of the

City of New York. Within the Medical Assistance Program (MAP) of HRA is the Home Care Service Program (HCSP). The HCSP contracts with existing and newly formed vendor agencies and oversees the budget management of the 62 independent not for profit vendors located within the five boroughs of New York City. The structure and operation of New York City vendor agencies are basically the same.[4] Each agency is overseen by a director, staffed by nurses and personnel specialists who coordinate the assignment of cases and working under HRA contract. Agencies vary mainly in location, contract size and the parent agency with whom they are affiliated.

In 1982, three unions, Local 1199 of the Drug, Hospital & Health Care Employees Union; Local 1707 of the Community and Social Agency Employees Union; and Local 32B-J of the Service Employees International Union, had succeeded in largely organizing this hitherto non-unionized labor cohort. While there are several benefits associated with unionizing a powerless work force of marginal workers, one direct result was that for the first time, it was feasible to study the demography, as well as the financial and medical needs of these women.

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[4] Caro, F., "Structure and Operation." Ibid.

The question of how the respective unions divided up organizing the workers is an interesting one, worthy of an historical study in itself; however no material has been written about that specific process. Inquiry with those working in the field suggests that when a union represented an existing social work agency and that agency in turn was awarded a home care contract by the City, the same union remained on to organize the HA's. An example is the Lenox Hill Neighborhood Association, whose staff was represented by Local 1199. When Lenox Hill became a vendor, its HA's were automatically organized by 1199.

CONTACT WITH LOCAL 1199

The decision to make contact with Local 1199 of the Drug, Hospital and Health Care Employees Union was based on two considerations. Local 1199, which represented approximately one-third of the total unionized work force, was perceived by the Home Care Council executives, the umbrella agency of all vendorized Home Attendant Programs, as most allied with the Home Care Council in negotiations. Furthermore, the history of Local 1199 suggested its commitment to improving the lives of oppressed workers, working women and minorities.

The cohort of Home Attendants, in addition to being the newest division of the union and the lowest rung of the

home care employees, is different from the other union members along several dimensions. Home Attendants, employed by vendor agencies (not hospitals), are assigned to work with an individual client (occasionally with a couple) in the client's home. Home Attendants can be viewed as the bottom rung of a two tier system within the union insofar as they receive a far less adequate salary and fringe benefit package than any other membership group of the union. On the other hand, if unionization had not occurred, they would have had no bargaining power or grievance procedure available to them. Insofar as Home Attendants are non-credentialed, in need of empowerment and primarily minority and immigrant women workers, they share some of the characteristics of the traditional early union membership.

In March of 1983, a phone contact was made with the then Vice-President of Local 1199 responsible for home care. Consultation with a Hunter College School of Social Work professor, Dr. Paul Kurzman, an expert in industrial social work, gave direction and advice for the first meeting. Over time, a joint proposal was developed between Local 1199 and Hunter College School of Social Work to allow for a needs assessment survey and demographic profile - the first study to be conducted with HA's. The second part of the proposal called for a case study of those women who would seek the help of the union. In fact, the act of defining HA's as a group in need and a cohort of interest to study can be seen

as representing a contribution to the field of social welfare.

The research arrangement agreed to by the union and the school was that the union would call various shop stewards to recruit the sample, provide coffee and carfare for study participants and provide funds for data analysis. In exchange, Dr. Donovan, this author and two second year Hunter College School of Social Work students, were involved in collecting the data by helping HA's to fill out the needs assessment questionnaire. The study would culminate in a written report to the union presenting the findings of the unmet needs. The case study of individuals needs and services would then be commenced.

Dr. Donovan's study, an extensive non-random needs assessment, conducted with groups of over 400 HA's at union headquarters, obtained evidence of the need for the establishment of a union-based social service program located at the union's headquarters. A summary of the findings of Dr. Donovan's study indicate that "as a group, the home care workers reported an average of 1.12 problems per family over the past year where they could have used help in solving the problem. Nearly half (44%) said they needed help with a housing problem; while 29% needed help with a health problem. Prevalence rates for other problems include: emotional problems (14%), legal problems (12%), child care problems

(10%),marital problems (8%), problems with child (8%), problems with child at school (8%)."[5] Additionally, this author, as an assistant to Dr. Donovan, did brief on-site interviews with some 200 HA's immediately after they completed the survey questionnaire. These interviews confirmed the fact that HA's could well benefit from the services of a trained social worker. HA's expressed needs for housing, education, individual and family counseling as well as legal and financial assistance even prior to analysis of the quantitative data.

In response to the needs discovered during on-site interviews and requests for help by workers, the union responded by developing a member assistance program. In the fall of 1985 Carol Rotman, who had been involved as the student research assistant for Dr. Donovan's study, was hired to run the MAP. This action, hiring a professional social worker to work on behalf of Home Attendants, represented a precedent in the union's history. It also can be understood as an example of social welfare's action-oriented research resulting in a service program. That is, research, through documentation of unmet needs, was the impetus for the creation of a program where none had existed before. Shortly thereafter, the service was expanded through the field place-

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5 Donovan, R. "Health and Social Needs," 4.

ments of Hunter undergraduate sociology students and subsequently by two graduate social work interns who each receive stipends, provided by Local 1199. As of 1991, two student with stipends continue in field placement at the setting, under Ms. Rotman's supervision.

Over time, and in part as a consequence of the relationship built between the university and the union, organizational sanction was obtained for the current study. The process of gaining this sanction is worth describing.

CONTINGENCY PLANNING

The relationships established with the union leadership and Hunter College School of Social Work faculty and students and the successful completion of Dr. Donovan's study allowed for the assumption that an on-site case study could be conducted with those women who had sought help at the member assistance program. After a turbulent change of leadership at Local 1199, new bridges were built. One of the "old guard" organizers introduced this researcher to the new Vice President of Home Care. After the history and purpose of the study was described, several conflicts were anticipated as barriers (organizational resistance) that might need to be overcome. Would the "old guard's" approval of the case study turn the new leadership (who had displaced them) against the study? Would the new leaders want to spearhead their own study, independent of university leadership? Would

they have the same values and commitment to professional social work services for the unmet personal, social and emotional needs of their members?

While the support of the new Vice President was gained by the researcher, based in part on a trusting professional relationship in the past (she had worked in the hospital in which this author was a co-founder of Veritas, a drug abuse treatment program, to which the Vice President had referred adolescents), it was necessary to gain the approval of the executive board of the union. The Vice President requested a letter to present to the board which itemized the benefits of the study to the union. We can infer that any new initiative, especially from an outside source, will be met with some degree of organizational resistance. However, if the benefits are seen to outweigh the costs, approval will likely follow.

We can infer that the board approved the study for several reasons. The Vice President's judgement to endorse the study and see it as advantageous to her division was one positive factor. Additionally, the union saw the benefit of a study that would help to build the new member assistance program. Since the 18,000 Home Attendants were the newest union members, representing 18,000 votes, as well as a significant dues paying cohort, efforts by the union on their behalf would only help to gain votes and loyalty for the

newly elected administration. Furthermore, the fact that Donovan's data had been developed and successfully used, the minor level of risk involved in letting in this outsider and gaining the possibility of help in designing the newest program to the workers, and the minor costs to the union were other positive factors in gaining union approval. Since there are three unions involved in organizing HA's, it serves future as well as current Local 1199 needs to show their HA's what their union dues are paying for. A MAP and research to use in collective bargaining provide an edge.

The original proposal to the union called for a two tiered study. The first component, Dr. Donovan's needs assessment, providing quantitative research findings of unmet needs, was tier one to be followed up by this author's more limited qualitative case studies. The proposal for stage two involved a qualitative assessment, interviewing those HA's who had subsequently used the MAP to see if they had been helped, and to better understand the nature of the help they had sought. After the MAP had been in operation one month, this author reviewed the cases on which Carol Rotman had worked. The first ten women who had seen or spoken with her were called by this author to inquire about their satisfaction in being linked to services.

Within days of the data collection effort, it was clear that this procedure was flawed and that respondents

were reluctant and fearful to answer questions. Respondents were suspicious about how the author had acquired their names, and about the purpose of the study. Furthermore, this sampling procedure was skewed insofar as only HA's with problems were being included. As such, this information would not be representative and there would be question as to its accuracy -even if such data were accessible and forthcoming. In sum, while entry had been gained for this case method study, the research strategy was flawed. An alternative approach was developed.

The decision to change the research strategy and methodology from a case study of the women who had used the newly established Member Assistance Program at the union to an agency based quantitative study was grounded in a variety of factors. The union was in the midst of strong internal conflict around leadership. Despite the fact that the new leadership gave sanction for the study to continue at the union, the project remained vulnerable to that leadership. That is, the environment of the union was relatively unstable and sanction could have been withdrawn at any stage of the research effort.

Sensitivity to organizational culture, stability and awareness of the organizational exchanges are part and parcel of the work. The greater the degree of dependence a

study has on one host organization, when that host organization is the only site of data collection, the greater the potential for the project to be in jeopardy.

The decision to change the methodological implementation of study from a telephone survey to an agency-based administration of the questionnaire needs to be understood from a theoretical point of view insofar as principles of practice may be gleaned from this experience. Landau states that it is "...an obvious and 'rational calculus' to employ a pragmatic and experimental procedure: that is which permits several, and competing strategies to be followed both simultaneously and separately."[6] He goes on to say that "any methodology is to be valued only to the extent that it achieves systemically relevant goals..."[7]

Glisson[8] is in agreement with Landau in that methodology, by its nature, must consider all feasible alternative strategies in order to assure a favorable outcome. The process that Glisson advances is grounded in a holistic

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[6] Landau, M. "Redundancy, Rationality, and the Problem of Duplication and Overlap" Public Administration Review, (July/August 1969): 355.

[7] Landau, Ibid.

[8] Glisson, C. "A Contingency Model of Social Welfare Administration," Administration in Social Work 5, no. 1, (Spring 1987): 11-17.

approach to decision making which combines the need to look at both subsystems and the environment. The contingency model approach views the manager (researcher) as a "decision maker" who must consider the rational, systemic and human relations dimensions of the organization in choosing alternatives for action..."[9] The union is but one system related to and interdependent with the vendor agencies and the Home Care Council. Access was sought and granted by the management of vendor agencies rather than the union.

The new strategy, sampling workers from 50% of all Local 1199 (T=11) affiliated HAP's (20% of all Home Care Council agencies) was approved by the Dissertation Committee. The new effort would sample HA's at their agency sites using fifteen minutes of scheduled in-service training time. However, in order for respondents to be allowed by their union to participate in the study, it was necessary to secure a letter of endorsement from the union. (Appendix B) Once composed, it was signed by the vice-president of the union's Home Care Division on behalf of the local. Since the new site of data collection would be based at agencies, it was also necessary to gain as well the endorsement of the Home Care Council, the umbrella agency of all New York City Home Attendant Agencies, and then the approval of the executive of each participating agency.

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[9] Ibid., p. 15.

THE HOME CARE COUNCIL

The Home Care Council (HCC) is the organizing body representing the 62 vendor agencies who are contracted by New York City to provide Medicaid funded home care services. While agencies whose staffs are affiliated with Locals 1199, 1707 and 32 B&J are members of the HHC, this study limited itself exclusively to 1199-affiliated Home Attendant Programs. As a body, the HCC is committed to increasing public awareness of the home care arena and sees their function as educating and advocating on behalf of HAP's. In the way in which the union represents its workers, so too the HCC can be seen as a federation of vendor agencies whom they represent in negotiations with New York City and State funding and standard-setting bodies.

From 1981-1983 this author was a curriculum developer and trainer in a State sponsored program which trained hundreds of Personnel Specialists and nursing supervisors of HAP's. Furthermore, the author was a participant on an advisory committee with the elected representatives of the HCC. Relationships of trust and mutual respect had been built and the results of that training effort had been very well received. The researcher was not an organizational "stranger" to the HCC and/or many of the HAP executives. She was known and trusted.

When the time came to request a letter of endorsement from the HCC it was promptly provided (Appendix A). The umbrella endorsement had a positive influence of encouraging individual agency executives to open their doors. In fact, no agency declined the opportunity to use their site as a location for data collection.

Support and sanction was gained for this current study from labor and from management, based on respect for Dr. Donovan's study, the status and neutrality of a university, hands-on work with the Vice President of the Division and her members, past relationships with key members of the Home Care Council, the author's expertise as a trainer of the managerial and supervisory staff of Home Attendant Programs, a demonstrated respect for confidentiality, adherence to protocol, as well as the author's years of work on behalf of and in the gerontological community.

VENDOR HOME ATTENDANT PROGRAMS

All of the 62 vendor agencies are free standing voluntary agencies or departments of larger agencies or settlement houses or hospitals. They are private (voluntary) non-profit, single purpose or multi-purpose service agencies working under a purchase of service arrangement with New York City. The real management, in the sense of authority, is the

New York City Human Resources Administration which, through the Office of Home Care Services (a sub-agency of the Medicaid Assistance Program) has a vested interest in cost containment. Vendor agencies therefore can be understood organizationally as intermediaries between funders and personnel. This intermediary relationship is also the case in many other arenas of social service delivery systems in New York City. The voluntary child care agencies, under contract with the Child Welfare Academy of HRA, and the residential community based programs for the mentally ill, who are contracted by New York State's Office of Mental Health, are two examples of vendor agencies which are organizationally similar to vendor home care programs.

In any purchase of service arrangement, government makes a decision to not deliver services directly but to purchase them. The agencies then become an intermediary between government (funding) and recipients (clients). Vendors have two constituencies: their clients and their personnel. There is an inherent dilemma for vendors insofar as they are caught in an impossible squeeze between an ethical commitment to service, a contracted commitment to recipients and a fraternal commitment to staff. Since vendor agencies are not powerful, have modest budgets and most often

are single purpose agencies, government has the upper hand.

For the most part, vendor agencies have less prerogative and power. They must look at the trade-offs involved in being unionized. With a marginal work force, such as HA's, vendor agencies have something to gain in having a unionized shop. Traditionally, management only looks at the negative aspects of unionization. In single purpose vendor agencies, there are real benefits to unionization, better health care packages (a healthy work force is less costly than a sick one), a staff with greater morale due to the collectivity of a power great than themselves and, in this instance, a union with whom the agencies can ally on some political issues.

Vendorship is referred to as purchase of service. Government agencies may purchase services from whichever agencies are most compliant with meeting needs and demand. Furthermore, since all of the Home Attendant Programs are non-profit they have a greater penchant for being client-and worker-centered. The fact that they are located in the communities they serve rather than in centralized bureaucracies is an additional variable that renders them more sympathetic to the workers and clients who are their charge. Taking an overview of the larger organizational structure of the home care service delivery system would allow for seeing

the executives of vendor agencies (management) as middle management in function rather than as executive in function.

Agencies need and welcome help for their staff, many of whom live at an economic level just marginally above public assistance, because such help will make their managerial task easier, thus promoting greater client satisfaction, staff productivity, and ultimately, government contract compliance. Likewise, agencies concerned for their workers had an opportunity to gain knowledge about the needs of their workers and perhaps maintain a more stable workforce.

BENEFITS OF THE STUDY TO THE PARTIES

All participating sub-systems must experience some exchange, some reciprocal benefit, for the time and energy they invest in any effort. Motivations involve implicit and explicit exchanges. The union had a variety of motives for sanctioning this study, including attention to their newest and largest constituency, a product (the research findings) that would empower them with empirical evidence to use in future labor negotiations, enhanced legitimization and credibility to its larger membership, an expanded base to include Hunter College of the City University of New York, and an opportunity to bring greater attention to the arena of publicly funded in-home care. In addition, there was little direct economic cost to the union for all of these benefits, a guarantee of discretion and confidentiality, and some

prestige in being involved with a university-based action research project on behalf of their constituencies.

The Home Care Council, eager for an increased awareness of the home care arena, aware of the shared goals of their work and the social work profession, interested in the status afforded by being a part of a research effort, had only to gain from granting their approval. The executives are sensitive to the needs of their workers and, so, saw this study as but one opportunity to help workers.

The individual vendor agencies, assured by the approval of the Home Care Council, their umbrella advocate agency, saw participating in this study as an avenue that would expand public awareness of their work and as a potential source of help for their workers. Letters of endorsement were included along with a letter requesting permission to administer the survey to their employees (Appendix C). What is noteworthy is that there was unanimous agreement for participation by all solicited agencies. Additionally, a number of executives expressed the sentiment that "at last someone is trying to help home attendants." It is reasonable to infer that agencies feel concern for their front line employees as well as pressure to maintain a stable work force.

The benefits to Hunter College School of Social Work are that through Dr. Donovan's research an alliance was forged between university and labor. The graduate student who was a research assistant in Donovan's study was subsequently hired by the union, and two stipended internships were negotiated and integrated into the Home Care Division of the union. The MAP extended the School's World of Work concentration by creating stipended internships; by so doing, another avenue was opened to promote the school's World of Work commitment, to ties between the labor movement and the social work profession. The school's affirmative action quest was also advanced, (as the only City sponsored Master of Social Work program) in strengthening the work experience of low income minority women and meeting the needs of an historically progressive trade union.

With the sanction of the two formal organizations (1199 and HCC) that have direct influence on the agencies and the staff, the stage was set for the technical aspects of the methodology to be implemented.

PART II - TECHNICAL ASPECTS OF THE STUDY: GOALS, RESEARCH, DESIGN & TARGET POPULATION

The goals of this study are to:

1. Expand the state of knowledge about the demographic profile of home attendants.
2. To elaborate on their actual economic situation.
3. Add to the body of knowledge about their health including the rates and correlates of stress related disease.

THE RESEARCH DESIGN

The research design is an exploratory descriptive study of home attendants in New York City. In keeping with the mission of social welfare research, this study is an action oriented project. In general, it is an intervention employed to improve conditions by refining understanding, adding to the knowledge base and catalyzing the process of social action to further the end of social justice. It is an effort to operationalize values into actions, to contribute to greater equity for the group and their families, to enhance the quality of service and to increase the effectiveness of the agencies which employ them.

THE TARGET POPULATION

Epstein and Tripodi[10] define the target as "the population to which a program should direct its efforts...and state that "the extent of client need should be determined prior to program initiation through need assessment surveys."[11]

The target population of this study was a group of HA's employed in selected 1199 vendor agencies located throughout Brooklyn, The Bronx, Queens and Manhattan.

SAMPLE SELECTION

A two stage sample selection procedure was employed to obtain the data, first selecting the agencies to be studied, and then, the HA's within those agencies.

Of the 22 Local 1199 affiliated agencies, it was found that six agencies were located in Brooklyn, five in The Bronx, eight in Manhattan and two in Queens, with only one in Staten Island. Half (eleven agencies) were selected by taking every other agency on the list ("systematic sampling"). As such, three agencies or every other of the six sites were selected in Brooklyn, three in the Bronx, four in

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10 Epstein, I. & Tripodi, A. Research Techniques for Program Planning, Monitoring & Design. New York: Columbia University Press, 1977, p.80.

11 Ibid., 61

Manhattan and one in Queens (see Table I). Since only one agency is located in Staten Island, it was not included in the sample. The sample of eleven Local 1199 agencies represents 20% of all the agencies affiliated with the Home Care Council and 50% of all the local 1199 affiliated agencies.

Since two agencies were not available until October, 1987, two contingency local 1199 agencies in New York City were substituted for two of the pre-selected agencies. The contingency agencies were randomly drawn from the pool of agencies otherwise not included in the sample. The agencies that were sites for data collection are shown in Table II. HA's who were scheduled for in-service training were sampled during their training periods.

The percentages of the work forces that participated in the study varied somewhat by agency, varying from 4% to 23%. Four agencies had over 10% of their work force sampled; Six agencies had between 5% and 9% of the work force sampled. One agency had 4% of the work force sampled.

THE DATA COLLECTION INSTRUMENT

The instrument (Appendix E) is a self-administered questionnaire comprised of both "open ended" and "closed-ended" questions, eliciting both qualitative and quantitative data. It consists of 27 items. Given the known and anticipated needs and demographics of the target population, the

instrument contained questions that measure variables such as: marital status, age, and number and age of children, child care costs and provision, country of origin, educational background, length of employment, cost of housing, earned individual and total household income, knowledge of agency sponsored medical benefits and the existence of non-agency supplied medical benefits, annual medical expenses, source(s) of medical services, perceived importance of medical service and the incidence of stress-related illnesses.

The issue of stress related illness requires some explanation. No standardized list of SRI's exists. As such, the author chose to use Belle's[12] conceptualization. To quote Belle, "Many of the health problems the respondents reported are those typically associated with stress including: asthma, ulcers, colitis, tuberculosis, migraines, chronic colds, arthritis, recurring pneumonia, high blood pressure, alcoholism and obesity."[13] In addition to the conditions Belle addressed nerves, sleep problems and diabetes were added and colds were omitted from the list on the questionnaire. An "other" category was inserted to allow respondents to include any other concerns. This study suggests that since "stress has been implicated in the etiology

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[12] Belle, D. Lives in Stress: Women and Depression. Newbury Park, CA: Sage Publications, 1982.

[13] Ibid., 44.

of numerous physical and mental health problems,"[14] the SRI's reported might be understood as somatisations in which stress is expressed in illness in this population.

The questionnaire was pre-tested in a pilot study on April 16, 1987 at agency #9, Independent Living. The pilot study was not included in the survey. Revisions were made with specific attention focused on the clarity of language of each question, responding to the reality that for many HA's English is their second language and they often have had limited educational opportunities.

DATA COLLECTION & PROCEDURES OF THE STUDY

As part of their contracts, HAP's are obligated to conduct two in-service training sessions of three hours duration each per year. Agencies vary in the frequency of the in-service scheduling. Some agencies contacted in May, 1987, were not offering another in-service until October, 1987. Fortunately, the majority of selected agencies held ongoing weekly or bi-weekly sessions (see Table II). The author administered the survey during required in-service training sessions for HA's. The survey was administered in 15 minutes (as requested by the agencies) in order not to infringe on the six hour training requirement.

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[14] Ibid, 35.

Once a date had been offered by the agency, the author went to the site to administer the survey questionnaire herself. Since group size varied, it was necessary to survey a number of agencies two times to assure a minimum of 18 respondents from each agency (see Table II). Five agencies (numbers 3, 4, 6, 7 and 8) had groups of HA's who spoke only Spanish. Where this was the case, the nurse conducting the training translated each question and response option to the subjects, with the author present. Data collection began on June 13th at agency #1 and was completed on October 6th at agency #11.

An organization can ask employees to participate in a survey or study and by necessity they will tacitly agree. Yet for a questionnaire to be completed thoughtfully, candidly and as completely as participants are able, certain prerequisites are important. In general, confidentiality must be assured, informed consent should be achieved through a clear statement of the purpose of the survey, and participants ought to be able to decline participation. They need to understand why the study is being conducted and how the outcome could benefit them and others.

Given that the target population is a multicultural and relatively powerless group of women who may have been reluctant about participating, the following procedures were

uniformly adhered to as protocol in advance of the distribution of the questionnaire:

1. The researcher introduced herself and noted she was there with the approval of the union, the HCC, and their agency.

2. A brief summary of Donovan's research findings was given. The fact that ten other agencies and 400 other HA's were participating was also noted.

3. The telephone number of the union-based free social service program was given and its use was encouraged.

4. Recognition was given to the HA's contribution in helping the school and the union to learn about their circumstances and it was stated that the collective results would hopefully be published for the general public. Furthermore, they were told that their union and the member assistance program would be given copies of the results.

5. The word "Confidential" was typed on the first page of the questionnaire, and individual anonymity was guaranteed by the fact that the questionnaires were to be unsigned.

6. Questionnaires were pre-numbered to aid in analysis of the data and assured confidentiality by the omission of any means of identifying an individual.

7. The researcher stated the procedures in English, Spanish and French, depending on the group composition.

Anticipating that the participants in this study might be reluctant, suspicious and/or frightened about responding, the steps taken in the protocol were aimed at creating an alliance for this short term endeavor. It was clear, based on responses, questions and participation, that the participants felt a degree of safety. While no one declined to fill out the questionnaire, nearly one quarter of the respondents omitted information on household income. This was accounted for in the analysis of the data (see Chapter 4).

Participants were told that this study was interested in _them_ - not their clients: interested in their health, resources and children. Furthermore, the questionnaire intentionally avoided questions that, while interesting, might have raised anxiety. As such, questions of alien status, year of immigration and satisfaction with the job were omitted, as were questions regarding any history of public assistance. It was felt that pursuing these sensitive areas of inquiry might lead to the distortion or withholding of information.

Respondents in agencies designated in Table II as "Spanish" survey groups were comprised of exclusively Spanish speaking HA's. Thus, in agency 3, 6, 7 and 8, the nurse in charge did direct translation of the questionnaire, while the

author was present. This implies that some degree of trust existed between the nurse, a supervisor and the group.

In order to have a larger sample at agencies 2, 5 and 11, the nurse in charge distributed the questionnaire to a second group after observing how the author instructed the first group to fill out the questionnaire. To assure reliability and consistency, nurses were given a typed page of instructions (Appendix F). The author handed out 377 questionnaires; 57 questionnaires were completed under the direction of nurses. The goal of having a larger sample size for each agency outweighed the small chance of inconsistency of response that may have occurred between the author's handing out the forms and the nurses also handling out the forms.

A total of 434 questionnaires was collected. The strategy for analyzing the data (see Chapter 4) included the use of basic descriptive statistics - frequencies, percentages, central tendencies (i.e., mean, median and modes) and measures of variability (range and standard deviations). The research questions involving relations among variables involved the use of cross-tabulations, Pearson correlations and multiple regression analyses, all with the appropriate statistical tests of significance. These analyses were conducted in order to examine hypotheses about the relationships among variables, particularly the correlates of the number of stress-related illnesses (SRI's) reported by the HA's.

STRENGTHS & LIMITATIONS OF THE METHODOLOGY

Limitations

- The time limitation imposed by the agencies prevented use of a longer questionnaire. Furthermore, some questions which would have been interesting to investigate (history with Public Assistance, date of immigration) were omitted for fear of inhibiting the participants and/or giving a perception of placing them at risk of exposure to immigration authorities.

- The data cannot claim to be representative of the total universe since the sample drawn was from one union's membership. However, there is no reason to believe that members of this union are systematically different from Home Attendants who are members of other unions, or from those HA's who work in non-unionized agencies. Further, workers attend training sessions regularly, with no known systematic bias as to who attends when. Although a true stratified random sample was beyond the resources available for this study, it is unlikely that the workers attending these required training sessions at these agencies chosen as a purposeful sample, would be substantially different than the total population.

- The choice of keeping the questionnaire exclusively in English, forcing a reliance on nurse translators, may have allowed for a greater variation in the presentation of the questions. To some extent, different translators may have given their own emphasis to the questions, thus somewhat altering the intent. However, given that many of the items were demographic rather than interpretive, this may not prove to be a significant limitation. In addition, the administration of the questionnaire in the absence of the investigator might also have allowed for some variations in presentation.

- A proportionate sample of each agency's work force might have yielded a more representative sample. The smallest percentage of respondents from one agency was 4.1% and another was 4.8%, while all others were over 5%; in four sites over 10% of the work force was tapped.

- No attempt was made to stratify by category of HA, by age, ethnicity, years on the job, etc. Individual interviews, however, might have proved more informative in terms of the qualitative material.

__Strengths__

This on-site survey allowed for a cost effective and time efficient means of data collection.

- While it cannot be stated that this study sample of Local 1199 agencies is representative of all of the universe of Home Care workers in New York City, there are no known differences among agencies other than size and location. Caro[15] makes the point that all of the vendor agencies operate under the same administrative structure and operative procedures.

- One additional advantage of the study was that participants were informed of the existence of their union-sponsored service program. This may improve participants' perception of their union as well as increase the utilization of the service.

- This study brings needed attention to the arena of in-home care. If the needs of HA's are addressed, the quality of service may be enhanced.

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15 Caro, F. "Structure and Operation," Ibid.

- When the general public realizes that their own families may be in need of care, a broader base of support may be organized.

- The positive alliance and ongoing relationship between Hunter College School of Social Work and the union fulfills a mission of the social work profession.

- Stipended student internships negotiated for in the process of contact with the union around this study, benefit the World of Work while offering students an important training ground.

The next chapter will present the results of the study.

TABLE I

GEOGRAPHICAL DISTRIBUTION OF HOME CARE COUNCIL AGENCIES

BOROUGH	TOTAL	1199*	SAMPLE
Brooklyn	21	6	3
Manhattan	19	8	4
Bronx	12	5	3
Queens	9	2	1
Staten Isl.	1	1	0
TOTAL	62	22	11

* Of the twenty-two 1199 affiliates, 11, or 50%, were selected.

TABLE II

SCHEDULE OF DATA COLLECTION

Agency	Borough	Month 1987	Agency Caseload Size	Size of Sample	Percent of Estimated WorkForce
1. Sunnyside	Q	June & Sept.	200	47**	23.5%
2. Caring Neighbor	M	July	200	47*	23.5%
3. Council for Human Service	M	October	400	20***	5%
4. Mobilization for Youth	M	July	400	20	5%
5. Salem Home Care	M	July	400	44*	11%
6. Seneca	Bx	July	200	18	9%
7. Puerto Rican Home Attendant Program	Bx	July	600	35***	5.8%
8. Bronx Council	Bx	June	600	25***	4.1%
9. Family Home Care	Bklyn	July	1000	112**	11.2%
10. Home Care Service for Independent Living	Bklyn	June	600	42*	7%
11. United Home	Bklyn	October	600	29*	4.8%
TOTAL				439	

* Agencies where two groups were sampled: One by the author and the second by a nurse.

** Agencies where the author administered the survey to two groups without the assistance of a nurse.

*** SPANISH - Groups were exclusively Spanish speaking.

CHAPTER IV - FINDINGS

This chapter will describe the results of the survey which sampled 434 Home Attendants, working in 11 different Local 1199 unionized Home Attendant Programs. A demographic, job and health profile of the Attendants will be followed by a detailed analysis of their economic situation. Their standing in relation to poverty level income standards will be compared to national poverty levels, as well as to Public Assistance (PA) and Medicaid (MA) eligibility levels. The number of Stress Related Illnesses will be shown and the correlates and predictors of having SRI's will also be shown for this population.

The decision to do a demographic profile was determined by the virtual absence of any such profile, with the one exception of Dr. Donovan's study. Given the time constraints imposed by the agencies, the decision to focus on the health and economic conditions of these women was grounded in the fact that health and economics are truly "common human needs" which are relatively objective and measurable elements of life satisfaction. If workers are too ill to work they are prevented from contributing to the labor force, risk falling into the chains of welfare and are compromised in their ability to care for their own children.

Likewise, if they are so impoverished as to be unable to adequately meet the needs of their families, they are more likely to have to retreat into becoming public assistance recipients, taking, when unable to contribute.

DEMOGRAPHIC CHARACTERISTICS

Home attendants are almost entirely female and are primarily foreign born, middle aged, with limited formal education and income. Most support their children on the income generated from their job.

As shown in Table 1, fully 99% of the Home Care Workers are female. About one third are married, one third divorced and one third never married (Table 2). The average age of the Home Care Workers in this study is 43 with a range from 19 to 69. However, 50% are between 30 and 49 years of age (Table 3).

Seventy-six percent of the respondents have children; those with children have an average of 2.7 (Table 4). In addition, 15% of the Home Care Workers have one or more children under six years of age (Table 5). The child care arrangements for these youngsters are divided among day care centers (37%), relatives (22%), friends (22%), neighbors (11%) and other (8%) (Table 6). The mean family size is 3.3, but almost one fifth (22%) are single person households (Table 7).

TABLE 1.

Gender

Gender	%
Female	99
Male	1
Total %	100%
Total No.	(434)*

TABLE 2.

Marital Status

Marital Status	%
Married	34
Divorced, Separated	27
Single	30
Widowed	9
Total %	100%
Total No.	(428)

* The N changes based on the number of respondents to each question

TABLE 3.

Age in Years

Age	%
19-29	17
30-39	25
40-49	25
50-59	22
60-69	11
70 or more	0
Total %	100%
Total No.	(417)
Mean (yrs)	43
St. dev. (yrs)	12
Minimum (yrs)	19
Maximum (yrs)	70

TABLE 4.

Number of Children

Number of Children	%
None	24
One	20
Two-three	36
Four-five	15
Six-seven	3
Eight or more	3
Total %	101%
Total No.	(409)
Mean (with children)	2.7
St. deviation	1.7

TABLE 5.

Number of Children Under 6

Number of Children	%
None	85
1	11
2	4
Total %	100%
Total No.	(408)

TABLE 6.

Child Care Arrangements for Those with children Under 6*

Arrangements	%
Day care center	37
Relative	22
Friend	22
Neighbor	11
Other	8
Total %	100%
Total No.	(82)

*15% of the sample have childen under 6.

TABLE 7.

Family Size

Family Size	%
One	22
Two-three	39
Four-five	25
Six-seven	10
Eight or more	4
Total %	100%
Total No.	(434)
Mean	3.3
St. Deviation	2.0

Brooklyn and Manhattan are the most frequent locations for both work (42% and 30%) (Table 8) and residence (51% and 20%) (Table 9). Half of the sample are high school graduates (Table 10). Fully 74% are not born in the continental United States and 63% are from the West Indies. The most frequently represented countries are the continental United States (26%), Haiti (18%), Jamaica (11%) and Puerto Rico (10%) (Table 11). Eighteen percent of the sample is monolingual in Spanish. The questionnaire to this group was printed in English and verbally translated into Spanish. About half the sample was Spanish/English bilingual, and they were able to complete the English language questionnaire (Table 12).

ECONOMIC CHARACTERISTICS

Close to two thirds of the Home Care Workers sampled are the sole wage earners of their households (Table 13). The average length of time the attendants have been employed in the home care field is 62 months (5 years and 2 months) (Table 14). Therefore, this sample is a relatively stable work force, perhaps because they lack alternatives, have limited education and/or lack English skills. Sixty-four percent are full time employees (Table 15), but a full 62% of the part time workers sampled would prefer to work full time (Table 16). Part time workers work an average of

TABLE 8.

Borough Attendants Work in

Borough	%
Brooklyn	42
Queens	11
Manhattan	30
Bronx	18
Staten Island	0
Total %	101%
Total No.	(429)

TABLE 9.

Borough Attendants Live in

Borough	%
Brooklyn	51
Queens	10
Manhattan	20
Bronx	19
Staten Island	0
Total %	100%
Total No.	(415)

TABLE 10.

Completed High School

Completed High School	%
No	50
Yes	50
Total %	100%
Total No.	(424)

TABLE 11.

Region of Birth*

Region of Birth	%
Continental U.S.	26
Puerto Rico	10
Other West Indies	53
Central & South America	10
Other	2
Total %	101%
Total No.	(422)

* West Indies includes Haiti (18%), Jamaica (11%), Dominican Republic (8%), Guyana (6%), Trinidad-Tobago (4%), Cuba (2%), Grenada (2%), Barbados (1%), St. Vincent (1%). Nevis and St. Thomas have less than 1% each.

Central and South America include Honduras (4%), Colombia (2%) and Chile (1%). Guatemala, Panama, El Salvador, Argentina, Belize, Brazil and Curacao have less than 1% each.

Other includes Liberia (1%) and USSR (1%). England, Greece, Switzerland and other African countries have less than 1% each.

TABLE 12.

Monolingual Spanish

Monolingual Spanish	%
No	81
Yes	19
Total %	100%
Total No.	(434)

TABLE 13

Sole Wage Earner in the Household

Sole Wage Earner	%
No	36
Yes	64
Total %	100%
Total No.	(409)

TABLE 14.

Length of Time Employed as a Home Care Worker

Years Employed	%
Two years or less	27
Up to 5 years	35
Up to 10 years	27
Over 10 years	10
Total %	99%
Total No.	(392)
Mean	5 yrs, 2 mos.
St. dev.	4 yrs, 5 mos.

TABLE 15.

Work Full-time or Part-time

Work	%
Part-time	36
Full-time	64
Total %	100%
Total No.	(421)

TABLE 16.

Prefer to work full time (Part-time workers only)

Prefer Full-time	%
No	30
Unsure	8
Yes	62
Total %	100%
Total No.	(145)

TABLE 17.

Hours per week for part-time workers

Hours per week	%
Up to 10 hrs.	10
11-20	35
21-30	41
31 or more	14
Total %	100%
Total No.	(122)
Mean (hrs)	23
St. dev. (hrs)	10

23 (Table 17) hours weekly and are precluded from receiving agency sponsored medical benefits.

The average monthly household income for the Home Care Workers in this study is $831 (Table 18). However, about one quarter of the sample did not give information on their household income. Many of the one quarter indicated their own income from the agency but omitted their total household income. Reasons for this omission may be that they had no additional income, or had very little additional income but neglected to say so. It is possible that they do not know the total household income because they are part of the Latin/Caribbean culture in which men do not tell their wives what they earn or their partners are undocumented and they do not want their income known or traced. Their average monthly rent is $361 indicating that, on average, workers spend 43% of their income on housing (Table 19). The 19% who pay for child care spend an average of $152 monthly (Tables 20 & 21).

POVERTY LEVEL

The poverty level, as determined by the United States Bureau of Labor Statistics, is computed as the equivalence of three times the cost of a minimally adequate diet.

TABLE 18.

Total Annual Household Income

Annual Income	%
Less than $5000	6
5001-6999	12
7000-8999	19
9000-10999	14
11000-12999	17
13000 or more	32
Total %	100%
Total No.	(330)
Mean Income ($)	11,823
St. Dev. ($)	6,071

TABLE 19.

Rent per Month in Dollars

Rent per Month in Dollars	%
$1-199	9
200-299	23
300-399	29
400-499	23
500-599	9
600 or more	7
Total %	100%
Total No.	(388)
Mean ($)	361
St. Dev. ($)	139

TABLE 20.

Pay for Child Care

Pay for Child Care	%
No	81
Yes	19
Total %	100%
Total No.	(434)

TABLE 21.

Amount Paid for Child Care Per Month

Amount Paid for Child Care	%
Less than $100	22
100-199	47
200-299	25
300 or more	6
Total %	100%
Total No.	(81)
Mean paid ($)	152
St. Dev. ($)	82

"It is based on temporary emergency food rations...."[1] However, it is widely recognized that Public Assistance levels are well below the poverty line. Furthermore, the poverty level itself is an inaccurate and insufficient measure of the economic level required to live in New York City. Even if one agrees to an absolutely conservative concept of poverty, a number of authors[2] suggest that computing 150% of the poverty level (the poverty level plus 50%) is a more realistic level in measuring economic misery. It should be noted, however, that families within even 185% of the poverty level are eligible for reduced fee school lunch programs, food stamps and Medicaid in New York City.

The 1987 federal poverty levels were compared with the income levels and household composition of the Home Attendants, in order to see the extent to which working in the home health industry was a hedge against poverty. (See Chart I) Table 22 reveals that 24% of the sample is below 75% of the poverty level, 44% are at or below the poverty level and fully 71% of the workers fall below 150% of the poverty level. Clearly then, when we speak of the working poor, Home Attendants qualify. In 1987 23.2% of the population of New York City lived at or below the poverty level as

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1 Vosler, N. "Assessing Family Access to Basic Resources" <u>Social Work</u> 35, no. 5, (September 1990): 434-443.

2 Katz, D. <u>The Undeserving Poor</u>. New York: Pantheon Books, 1989.

Chart I.

1987 National and New York City Poverty Data

1987 National Poverty Levels

Family Size	Gross Income
1	$5,778
2	7,397
3	9,056
4	11,611
5	13,737
6	15,509
7	17,649
8	19,515
9	23,105

1987 New York City Poverty Figures

At or below % Poverty Level	Percent
75%	17.3%
100%	23.2
150	32.0

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*Source: Dependency: Economic and Social Data for New York City, Human Resources Administration. Office of Policy and Program Development. June 1988.

TABLE 22.

Percentages of Sample Below Poverty Level

Percentages Below	%
75% of poverty level	24
Poverty level	44
150% of poverty level	71
Total No.	(330)

* These categories are overlapping in that Attendants who are below 75% of the poverty level are also below the two higher levels, and those below poverty level are also below 150% of that level.

compared to 44% of the HA's. Furthermore, while 32% of the general population of New York City were at or below 150% of the poverty level, HA's, as a group, have more than twice the incidence of poverty than does the general population. When close to half the population sampled (44%) are at the poverty level, when that level is one of mere subsistence, one must ask about the incentives involved in gainful and helpful employment.

ELIGIBILITY FOR PUBLIC BENEFITS

It was postulated in Chapter I that an alternative definition of home care was to conceptualize it as a public works program in which a necessary and important community-based social health service was being provided to a poor, infirm and dependent population by supplying "cheap labor"; some of whom might otherwise be eligible for public assistance and/or Medicaid. While it would have been too delicate to inquire if any of these women had formerly been recipients of Aid to Families and Dependent Children (AFDC), public assistance workers and agency-based social workers have referred their clients to this occupation. In other words, the home care arena may provide a workfare-like alternative to public assistance recipients.

One thesis advanced by this study was that the HA could well be seen in social work conceptualization as a client, lacking knowledge of or access to the array of ex-

isting public benefits and entitlements which might supplement their income and health care coverage and enhance the quality of their lives.

The analysis of public assistance and Medicaid eligibility sought to determine the characteristics, within the sample, of the most economically vulnerable sub-group. In order for an accurate determination, it was necessary to consider family size insofar as income is a meaningless variable without consideration of relative need.

Total monthly household income and family size were compared to Public Assistance and Medicaid eligibility levels (see Appendix G) to see how many workers were so poor that they are eligible for benefits. Close to one quarter (22%) of the total sample are eligible for Public Assistance (PA) and close to one third (32%) are Medicaid (MA) eligible. (See Tables 23 and 24). We can assume that this cohort is the most economically vulnerable group within the sample. What is evident is that many more HA's are eligible for MA than receive it, and that some women are PA eligible and are not receiving aid. To the extent to which people eligible for benefits do not utilize them, the government saves money. A separate profile of the demographic features of the Medicaid eligible and Public Assistance eligible workers is worthy of description in order to see if they have any special characteristics. Exact income and family size was calculated

TABLE 23.

Eligible for Public Assistance

Eligible for PA	%
No	78
Yes	22
Total %	100%
Total No.	(330)

TABLE 24.

Eligible for Medicaid

Eligible for Medicaid	%
No	68
Yes	32
Total %	100%
Total No.	(330)

for each respondent and compared to eligibility criteria for the year in question.

As shown in Table 25, 92% of those who are MA eligible are sole wage earners as are 87% of those who are eligible for PA, while only 66% of those eligible for neither are sole wage earners. Thus there is a positive relationship between being the sole wage earner and likelihood of eligibility for public benefits. (r=.21, sig=.000)

Only 42% of those who are MA eligible and 41% of those who are PA eligible are full time workers as compared to the 80% of full time workers whose income makes them ineligible for benefits. Full time workers are therefore much less likely to qualify for benefits. (r=.-36, sig =.000; see Table 26.)

As discussed in Chapter III, the concept of SRI's, while not a uniform category, uses Belle's conceptualization. However, the National Interview Survey[3] defines seven chronic conditions which were incorporated into the questionnaire used in this study: arthritis, asthma, colitis, diabetes, hypertension, migraines and colitis. The trend is that

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[3] Adams, P.F., Hardy, A.M. "Current Estimates From the National Health Interview Survey: United States, 1988." National Center for Health Statistics, Vital Health Statistics 10, no. 173 (1989).

TABLE 25.

Sole Wage Earner by Medicaid and Public Assistance Eligibility

Sole Wage Earner	Medicaid and Public Assistance Eligibility: Neither	Medicaid Only	PA
No	34%	8%	13%
Yes	66	92	87
Total %	100%	100%	100%
Total No.	224	49	55

r = .21, sig. .000

TABLE 26.

Working Full Time by Medicaid and Public Assistance Eligibility

Work Full Time	Medicaid and Public Assistance Eligibility: Neither	Medicaid Only	PA
No	20%	58%	59%
Yes	80	42	41
Total %	100%	100%	100%
Total No.	223	48	56

r = -.36, sig. = .000

those who are PA eligible (the poorest) have the most SRI's (36% with two or more) as compared to 29% of those who are MA eligible and the 27% of those who are not eligible for benefits, however this relationship is not statistically significant. (r=.07, sig-.096; Table 27) Likewise, 55% of the PA eligible reported having a current medical problem as compared to the 46% among those who are MA eligible and 44% among those not eligible. There is, thus, a slight positive correlation between being PA eligible and currently having an illness, suggesting that the poorest women are more likely to be more ill, although the relationship is not statistically significant at the .05 level. (r=.08, sig=.084; Table 28.)

The remaining characteristics were not significantly related to eligibility: knowledge of English, region of birth, graduating from high school, time on the job, hours worked by part time workers and family size.

Several HA's chose to comment on their needs in response to an open-ended question. Fifty-one stated they deserve better pay, 16 stated that their income was inadequate, 16 wanted more full time work, 15 felt it unfair that

Table 27.

Number of Stress-Related Illneses by Medicaid and Public Assistance Eligibility

	Medicaid and Public Assistance Eligibility		
Stress-Related Illnesses	Neither	Medicaid Only	PA
None	35%	35%	27%
One	38	37	38
Two or more	27	29	36
Total %	100%	101%	101%
Total No.	225	49	56
Mean	1.2	1.1	1.4

r = .07, sig. = .096

Table 28.

Have a Medical Problem Now by Medicaid and Public Assistance Eligibility

	Medicaid and Public Assistance Eligibility		
Medical Problem Now	Neither	Medicaid Only	PA
No	56%	54%	45%
Yes	44	46	55
Total %	100%	100%	100%
Total No.	213	46	53

r = .08, sig. = .084

they sleep in (when working on 24 hour assignments) yet get paid for only 12 hours, eight complained that their paychecks were late, five wanted more pay for overtime and one woman indicated that she needed food stamps. It is likely that a significant percent of women are eligible for food stamps, however these calculations were not made.

In sum, of those who are MA or PA eligible, the primary characteristics, besides their lower income, are that fewer are currently married, more are the sole wage earners and more are employed part-time. These characteristics lead to great likelihood of eligibility for public benefits.

HEALTH

Home Attendants are, by definition, health care workers. Yet, if they are working in an occupation made stressful by the structural conditions of employment, lack of: career ladder, career mobility, supervision, adequate training, incentives, a sufficient health benefits package and job stability, it is important to assess the health of the health care providers. On the assumption that there would be a higher incidence of stress related illness, a significant out-of-pocket expenditure for their own health care needs and the possibility of illness preventing them from consistent work, an analysis of their incidence of stress-related illness was computed.

The questionnaire gave respondents a checklist of 14 stress related illnesses (SRI's) which they might have had in the past two years. The list was taken from Deborah Belle's study, Lives in Stress.[4] The average number of stress related illnesses reported per Home Care Worker was 1.1. (Table 29) About one third reported that they had no illnesses, about one third reported that they had one, and the remainder had two or more illnesses. The most common illnesses were: hypertension (19%), weight problems (18%), arthritis (17%) and migraines (12%) (Table 30).

While it is helpful to know the prevalence of the most common illnesses reported for this population, the statistics are more meaningful when compared to the national prevalence rates.[5] While 19% of the study respondents have hypertension, the incidence in the general population is 12.2 percent. While 18 percent of the HA's reported having arthritis, the incidence for the general population is 13 percent. The National Survey data included people of all ages, wherein this study surveyed adults only, therefore it is probably that the incidence of hypertension among HA's is close to twice the national average. Alcoholism was not reported at all. Given the high incidence of this disease among the general public, it is unlikely that there is no incidence within this cohort. However, in a self-report

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4 Belle, D., Ibid.

5 Adams, P.F., Hardy, A.M., Ibid.

survey administered at a work site, reluctance to admit substance abuse is a highly likely.

Only 38% of the full time Home Care workers knew what their health insurance covered (Table 31), suggesting that agencies and the union would do well to assure that knowledge of benefits be a subject for education. Only 16% (Table 32) had additional health coverage other than from their agencies. Only 10% had Medicaid, 5% had Medicare, and 15% had coverage from a family member. Ten percent had Medicaid for their family and 2% of the children were receiving Medicare. (Table 33) As stated earlier, fully 32% were Medicaid eligible yet only 10% were receiving this entitlement.

Forty-two percent currently have a medical problem requiring ongoing medical care (Table 34), although only 16% say they have missed out on an assignment due to illness (Table 35). This strongly suggests that these workers are working while ill, with economic necessity overriding medical concern.

The average annual out-of-pocket medical expenses for 1986 were $783, the equivalent of one months salary for close to half of the sample. The standard deviation was even higher ($856), indicating a wide range in medical expenses; e.g., 8% spent $2,000 or more (Table 36). Not surprisingly,

TABLE 31.

Do you know what your agency health insurance covers?
(Full time workers only)

Know Coverage	%
No	39
Not sure	23
Yes	38
Total %	100%
Total No.	(265)

TABLE 32.

Have Medical Coverage Other than Agency Coverage

Have Other Coverage	%
No	82
Not sure	2
Yes	16
Total %	100%
Total No.	(423)

TABLE 33.

Other Types of Medical Coverage*

Other Types of Coverage	%
Medicaid	10%
Medicare	5
Coverage from other family member	15
Medicaid for children	10
Medicare for children	2
Total No.	(434)

* Respondents could check more than one category.

TABLE 34.

Have Current Medical Problem Requiring On-Going Treament

Have Current Med. Problem	%
No	58
Yes	42
Total %	100%
Total No.	(400)

TABLE 35.

Illness Has Caused Attendant to Miss Out on a Client

Have Lost Client	%
No	84
Yes	16
Total %	100%
Total No.	(350)

TABLE 36.

Out-of-Pocket Medical Expenses in 1986 for Self and Family

Medical Expenses	%
Less than $200	9
201-399	23
400-599	25
600-999	18
1000-1499	12
1500 or more	13
Total %	100%
Total No.	(302)
Mean ($)	783
St. Dev. ($)	856

TABLE 37.

Importance of Improved Medical Benefits

Importance	%
Not important	0
Somewhat	4
Very Important	96
Total %	100%
Total No.	(397)

almost all (96%) indicated that improved medical benefits were very important to them (Table 37).

Despite their limited formal education, many HA's wrote in comments about their health needs. For example, 72 stated that they need better medical benefits, 19 requested medical coverage for physicians, 17 stated that they needed dental benefits, 7 requested help to obtain Medicaid, 4 requested discounts on medication and 3 indicated that coverage for eye examinations would be helpful.

CORRELATES OF STRESS RELATED ILLNESSES

As described above, 36% of the Attendants reported having no stress related illnesses, 36% reported one, and the remaining 28% reported two or more, for an average of 1.1 per respondent. A detailed bivariate and multi-variate analysis was undertaken to isolate the factors which related to having SRI's in this occupational group.

The results show that the number of SRI's is significantly positively related to age, number of children, number of hours worked per week (for part-time workers), and eligibility for public assistance. The number of SRI's is negatively correlated with working full time and the amount paid for child care. In addition, SRI's are highest among those who work in Brooklyn and the Bronx. The number of

SRI's is not significantly related to the other characteristics of this study, including being married, education, region of birth or Spanish monolinguality.

Women over 50 have the most SRI's and the youngest women have the fewest SRI's, showing that the incidence of SRI's increases with age. (r=.15, sig=.001, Table 38)

Family size is mildly correlated with the number of stress related illnesses (r=.12, sig= .006, Table 39), as is the number of children (r=.15, sig=.002). Family size, of course, reflects the number of children.

Part time workers have a greater incidence of SRI than full time workers. (r=.16, sig=.040, Table 40) It is difficult to infer from Table 40 if part time workers work part time due to their medical status, or if working part time and therefore having less income might be a factor related to the SRI's.

There is a mild positive trend, though not quite statistically significant, between eligibility for public assistance and their incidence of stress related illness. (r=.08, Sig=.080) As shown in Table 41, 35% of those ineligible for benefits had no SRI's compared with 27% who were eligible for public assistance. Likewise, 27% of those

Table 38.

Number of Stress-Related Illnesses by Age

Illnesses	Under 30	30-39	40-49	50 or over
None	51%	38%	32%	28%
1	27	38	38	39
2 or more	22	24	30	33
Total %	100%	100%	100%	100%
Total No.	71	104	106	136

r = .15, sig. = .001

TABLE 39.

Number of Stress-Related Illnesses by Number of children

Illnesses	None	1	2	3+
None	42%	45%	27%	29%
1	38	26	42	36
2 or more	20	29	30	34
Total %	100%	100%	99%	99%
Total No.	97	80	95	137

r = .15, sig. = .002

TABLE 40.

Number of Stress-Related Illnesses by Hours Worked Per Week
(Part-Time Workers only)

	Hours Worked per Week					
Illnesses	1-10	11-15	16-20	21-25	26-30	31+
None	40%	36%	33%	31%	18%	29%
1	40	43	37	38	41	24
2 or more	20	21	30	31	41	47
Total %	100%	100%	100%	100%	100%	100%
Total No.	10	14	30	29	22	17

r = .16, sig. = .040

TABLE 41.

Number of Stress-Related Illnesses by
Whether Attendant is Eligible for Public Assistance

	Eligible for Public Assistance		
Illnesses	No	Yes	
None	35%	27%	r = .08,
1	38	38	sig. = .080
2 or more	27	36	
Total %	100%	101%	
Total No.	274	56	

r = .08, sig. = .080

ineligible had two or more SRI's compared with 36% who were PA eligible.

Those women who pay more money per month for child care have fewer SRI's; 62% of the women who pay over $250 have no SRI's compared with 42% who have no SRI's but pay $50 or less per month. There is a negative correlation between the amount of money paid for child care and SRI's. ($r=-.22$, sig=.025, Table 42) It makes sound psychological sense that women who pay more for child care have fewer SRI's. The economic cost is well worth the emotional security.

Women who work in the Bronx have the greatest incidence of two of more SRI's (36%) followed by women who work in Brooklyn (34%), Queens (26%), and Manhattan (16%). These differences are significantly at the .008 level. (Table 43) However, it seems unlikely that the relationship of the variables is related to borough rather than some other difference between these groups. These women presumably have longer travel time commuting on dangerous subways and this may be an important factor.

American-born women have the greatest percent, with two or more SRI's (36%) followed by Central Americans (33%). Twenty five percent of West Indian and South American women have two or more SRI's. (sig=.161, Table 44)

TABLE 42.

Number of Stress-Related Illnesses by Amount Attendant Pays for Child Care Per Month

Illnesses	Amount Paid for Child Care per Month					
	To $50	51-99	100-150	151-199	200-250	251+
None	42%	0%	40%	46%	41%	62%
1	17	67	20	38	35	38
2 or more	42	33	40	15	24	0
Total %	101%	100%	100%	99%	100%	100%
Total No.	12	6	25	13	17	8

r = -.22, sig. = .025

TABLE 43.

Number of Stress-Related Illnesses by Borough of Employment

Illnesses	Borough			
	Brook-klyn	Queens	Man-hattan	Bronx
None	36%	33%	41%	26%
1	30	41	43	38
2 or more	34	26	16	36
Total %	100%	100%	100%	100%
Total No.	178	46	128	76

Sig. = .008

TABLE 44.

Number of Stress-Related Illnesses by Place of Birth

Illnesses	Place of Birth				
	U.S.	West Indies	Central America	South America	Other
None	29%	38%	19%	55%	33%
1	35	37	48	20	44
2 or more	36	25	33	25	22
Total %	100%	100%	100%	100%	99%
Total No.	108	264	21	20	9

Sig. = .161

It is quite likely that the reported SRI's are an underestimation of the actual number of SRI's in this community. Some of these working women may have been reluctant to admit illness. This group may include a silent and possibly long suffering contingent that would not complain about illness publicly or, perhaps, have disregarded symptoms which they accept as their "lot." Some of the women may not know how to name some of the symptoms they experience and/or have not been properly diagnosed. Furthermore, there are a lot of "not feeling well" physical symptoms that are never dignified by a label but are very debilitating, yet "sub-clinical." Symptoms described in their own language maybe have been omitted, such as chronic spasms, fatigue, mild dizziness, constipation and anxiety or tension states -- symptoms which require a very close look at the patient's phenomenology, and which require the use of their own language.

While it was found that 1.1 was the average number of SRI's, there are inherent limitations to averages. That is, one serious kind of hypertension may outweigh two other conditions which could co-vary. Furthermore, since some conditions often co-exist - say, hypertension and obesity - it is somewhat curious that so few women checked off more than one illness. This point of view is supported by the fact that 96% saw expanded health benefits as very important.

MULTIVARIATE ANALYSIS

A multiple regression analysis was performed to further analyze the factors which relate to having stress related illnesses. Although these factors have already been tentatively identified, results can be misleading because of the various predictive factors which are also, as a rule, correlated with one another. The relationship of any one of the variables to having SRI's, therefore, can be an artifact of its relationship to one of the other predictive factors. Multivariate analysis, e.g., the multiple regression analysis performed here and reported in Table 6, overcomes this difficulty, at least for the various predictors included in the analysis. Separate analyses were performed for the total sample and for part-time and full-time workers, on the possibility that some predictors might operate differently for these groups.

The key statistic in a multiple regression analysis is the beta (standardized regression coefficient), which isolates the separate and independent effect of each of the predictor variables.

As shown in Table 45, the most outstanding finding revealed by the regression analysis of full-time and part-time workers uncovered that working in Brooklyn is related to having more SRI's. No causality, however, can be claimed. (beta=.15, sig=.001). As was revealed in the bivariate

Table 45.

Predictors of the Number of Stress-Related Illnesses (SRIs) for All Home Attendants and Part-time and Full-time Attendants: Multiple Regression Analyses

Predictors	All Attendants r	All Attendants Beta	Part-time Attendants r	Part-time Attendants Beta	Full-time Attendants r	Full-time Attendants Beta
Born in U.S.	.07	.12***	.09	.10	.07	.11**
Born in Cent. America	.02	-.04	-.04	-.08	.04	-.03
Age	.15	.14***	.20	.22**	.16	.12*
Married Now	-.07	-.08	-.13	-.18*	-.04	-.02
Number of Children	.12	.11***	.09	.04	.16	.13***
Monolingual Spanish	.03	.11**	-.01	.04	.05	.15**
Completed High School	-.08	-.02	.03	.11	-.15	-.10*
Sole Wage Earner	.05	.04	.04	-.05	.06	.05
Income	-.04	.02	.01	.05	-.06	-.01
Pay for child care	-.06	-.02	.00	.04	-.07	-.04
Work in the Bronx	.08	.15***	.00	.09	.12	.18***
Work in Brooklyn	.08	.23***	.00	.08	.12	.30***
Work & live in same Boro	.02	-.10*	-.02	-.09	.04	-.12**
Working Full-time now	-.02	-.04				
Hours per week worked			.13	.12		
Multiple R		.29		.32		.36
Multiple R^2		.08		.10		.13

r = Pearson correlation coefficient; significance shown in Table 5. Beta = standardized regression coefficient; significance by F-test: * = .05, ** = .01, *** = .001. Multiple R shows the correlation of all the predictors combined with the dependent variable (no. of stress-related illnesses). Multiple R^2 shows the percent of variance of the dependent variable which is explained by this group of predictors.

analysis, predictably, the older one is, the greater the number of SRI's. In the regression analysis, age is again shown to be positively related to the number of SRI's. (beta=14, sig=.001) Being American-born is associated with a higher incidence of SRI's (beta=.12, sig=.001) as is the number of children one has (beta=.11, sig=.001). One finding obscured by the bivariate analysis but revealed in the multivariate analysis is that being monolingual Spanish is positively associated with the incidence of SRI's (beta=.11,sig=.01)

On the other hand, there are fewer SRI's for those who live and work in the same borough (beta =-.10, sig=.05), suggesting that commuting out of borough is a predictor of stress in this population.

While the patterns are the same for full-time and all workers, for the part-time workers only age was positively related, (beta=.22, sig=.01) and being currently married (beta=-.18, sig=.05) were predictors of the number of SRI's.

The multiple regression analysis proved a useful measure because the bivariate analysis masked several relationship which were revealed by the betas, e.g., the relationship for full time workers of being monolingual Spanish to having SRI's and the relationship of living and working in the same borough, to having fewer SRI's. The reader should

be cautioned that, based on the design of this study, causality cannot be established.

Multiple R^2 is literally the square of the multiple R. The multiple R is the correlation of all the independent variables together with the dependent variable. The multiple R^2 measures the percent of the variance of the dependent variable, which is statistically explained by all of the independent variables together.

In addition, the multiple regressions which range from .29 to .36 are within the range of those commonly observed in social science data. As commonly happens, the multiple regressions show that the independent variables together do not explain a large percentage of the variance of the dependent variable.

SUMMARY OF KEY FINDINGS

In summary, Home Attendants are self-supporting, foreign-born middle-aged women. They are high school graduates, raising their children on monies generated from the work they do as employees of Home Attendant Programs. They are living below, at or close to the poverty level and pay a very high percent of their income for shelter. They have remained on their jobs for an average of five years, pay taxes and work in a branch of the health care industry which lacks career mobility and/or career incentives.

We have learned that she needs and wants better wages, expanded medical coverage for herself and her children, inexpensive day care, to work in the borough in which she lives and needs to be educated about the job-related and public benefits for which she may be eligible.

Many of the hypotheses were borne out by the results. It was anticipated that not only were these women relatively unaware of the medical benefits that are part of their fringe benefits package, but that they also spent a disproportionately high percent of their income on medical expenses. In fact, they spend, on average, over 10% of their earned income on medical care.

Only 38 percent of the full time employees knew what their health insurance covered and their average out-of-pocket medical expense, for the prior year, was $783, close to one month's average income. It is possible that if they knew what their agency based health coverage reimbursed, they might be able to use their insurance to offset some of the costs. Clearly, reimbursed medical expense allows for more disposable income. Furthermore, improved health insurance makes it more likely that people will attend to their own medical needs. It is also possible that, given how meager their incomes are, they delay and/or avoid medical care, thereby inviting acute conditions to become chronic. This

could account for the fact that while 42 percent reported a current medical problem, only 16 percent had lost an assignment due to their own illness. One also wonders what accommodations they make when their children come down with the usual illness of childhood.

Since working while ill must have a negative impact on the quality of work performed and, indeed, could unnecessarily expose clients to infection, it is clear that workers must be informed about and encouraged to use the limited insurance provided to those who are full time employees.[6] Furthermore, their health insurance policy ought to be expanded to cover a greater spectrum of conditions and be converted to family coverage. While this study did not inquire about the health of their children, future research might explore this issue.

The hypothesis that these women want improved health care coverage was overwhelmingly correct insofar as 96 percent indicated that improved coverage was very important to them. It is likely that the 4 percent who indicated that improved coverage was only somewhat important either have coverage from a spouse or receive Medicare.

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[6] Prior to the 1988 contract negotiations, medical insurance coverage was restricted to 21 days in hospital, emergency first aid and $6 for office visits to physicians.

Another hypothesis of this study was that the prevalence of Stress Related Illness for this cohort would be as great if not greater than that of the general population (see page 113), alas this hypothesis was borne out by the findings in, and comparison with, the national results.

Physically, they suffer from an average of 1.1 stress related illnesses, preponderantly hypertension, obesity and arthritis. A good number of them have not availed themselves to the public benefits to which they are entitled, either due to ignorance, possible reluctance to come under the review of the government officials and the Immigration and Naturalization Service , or perhaps because the application process is long, time consuming and complicated. It is also possible -- based on cultural, religious, and/or personal values -- some women may reject the dependency that has been associated with receiving public entitlements.

In addition the study assumed that the work force was stable and that their disposable income would qualify them as living in or near the poverty level. Indeed, the work force proved to be remarkably stable with the average time on the job at over five years. Furthermore they are a motivated work force. That is, of the 36 percent who are part time workers, 62 percent would prefer to be employed full time. This finding is of particular relevance given the unusually high turnover often associated with other direct

care jobs: Nurses Aides, group home workers, and community based mental health therapy aides.

The assumptions about their economic conditions were only too correct. Home attendants are the personification of the working poor. A full 44 percent are at the poverty level, that income level calculated as three times the cost of a minimally adequate, temporary, emergency food ration. In 1987 23.2 percent of New Yorkers were living in poverty compared with 44% of Home Attendants. When these same figures were compared to those living within 150 percent of the poverty level, a commonly accepted definition used to compensate for the poverty level which is unrealistically low, 32 percent of New Yorkers were at this level of poverty compared to 71 percent of the Home Attendants. It cannot be disputed that Home Attendants, those serving the needs of the elderly and the impoverished who are functionally disabled, are overrepresented in poverty despite the central role they play in helping to maintain people out of much more expensive institutions.

In line with the economic circumstances of these women, a simply calculus was employed to determine those who would be eligible for public benefits. Due to the minimal wages they earn it is not surprising that 32 percent of the workers are Medicaid eligible and 22 percent are eligible for

public assistance. It is quite clear that Home Attendants have "inadequate access to adequate resources."[7]

Seventy-two women (22 percent) of the sample were eligible for public assistance. While it is not known how many were receiving this benefit there is something quite stark about the fact that in-home care can be likened to workfare. That is, welfare eligible women are providing public service to medicaid recipients. Two "client" groups are united, one to help the other, both impoverished, each with little incentive or supervision and, perhaps, hope.

While 32 percent of these women and their families are Medicaid eligible, only 11 women are receiving Medicaid. Had an income and family household comparison been made for the broader range of public benefits, it is likely that even more women in this sample would be eligible for the food stamps, section 8 housing, tuition assistance and home energy assistance programs. There is an irony here that speaks to a false economy. Medicaid is a publicly funded social provision, a residual program, which by definition is paid for out of public funds. Since vendor agencies pay workers out of the pool of Medicaid funding, all of the monies in this system are public. An increase in salary would likely lessen eligibility for public benefits while concurrently enhancing

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[7] Vosler, N., 438.

self esteem and possibly, in turn, the quality of care provided. It is in everyone's best interest to invest in benefits as a condition of employment rather than a condition of dependence.

Government saves money when people who are eligible for benefits do not avail themselves to those benefits. We know that there are many more people eligible for public benefits than receive these entitlements. Social work has had a long tradition of information, referral assessment, education and advocacy on behalf of rights. It is in keeping with that proud historic tradition that Home Attendants become more of a focus for social workers.

However, even if all of the HA's eligible for public benefits were to be aided or directed or educated to apply for their legal entitlements, it is reasonable to assume that there is an emotional cost to the self, an additional source of stress to be a recipient of public benefits rather than a worker with wages and benefits that are stable and adequate.

Even if the money value of wages plus public benefits were equivalent to higher wages it is safe to assume, based on common wisdom and general psychology, that there is a net gain in self esteem and perhaps, by inference, in the quality of services, if entitlements are made a customary

part of the fringe benefits package of work. Given the high cost of health insurance coverage, in fact it would be unrealistic to expect that a slight increase in wages would offset the broad coverage provided by Medicaid. Therefore, as 96 percent of this sample indicated, it is necessary to expand existing medical coverage of the workers under their agency coverage. There is an ethical imperative to increase wages and expand health benefits for unionized home attendants in order to create "access to adequate basic resources."[8] It would be an unfortunate denial of reality and of common wisdom to believe that people can provide adequate care when their own needs have not been adequately secured.

One finding of particular interest is that of stability of this work force. The literature review in Chapter II cited the issue of turnover as a serious problem for hospital and nursing home based nursing aides. Similarly the turnover rate is high in numerous arenas of health and social service delivery: shelter care workers, foster care workers and community based mental health workers all share high turnover. While the reason for the stability of this workforce was not tested, the fact of their stability, whether grounded in lack of options or in loyalty and dedication

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[8] Ibid., 438.

to the work, is an attribute that ought to be noted, supported and further researched.

One unanticipated finding requires further research: the fact that the American born women in the sample, the vast majority of whom are Black, is the group reporting the greatest incidence of Stress Related Illness. However, the current speculation of this author is that while the immigrant women come to America with the hopes that historically have typified each wave of immigrant (hope for a better life for themselves and their children), the Black Americans have had those dreams dashed. While they have come from countries where they were the majority culture, they have never been a part of a majority culture in this country. They may represent and personify the negative impact of living in a society which offers limited access and resources to people of color. It would be interesting to review the literature in immigration and stress, but that is a direction for future research.

For many women, care taking roles, and caring for the elderly and infirm are a very important aspect of identity and/or may not be valued by our culture which demeans hands-on work by paying so little. Certainly, social work can and should recognize the value of direct care.

The findings are rather dramatic, in that a group of women work so hard, for long periods of time, with limited remuneration, raising children alone, lacking career ladders, and yet report relatively few illnesses, work while ill, and under-utilize public benefits. Fortunately, they have been able, through unionization, to demonstrate and bring greater public attention to their plight. Their organized protests have led to improved contracts.

CHAPTER V - SUMMARY AND IMPLICATIONS

THE HOME CARE WORKER

This study focused on one crucial element of the home care equation: the home attendant. The home attendant is without a doubt the single most influential service provider in the home care system. While other disciplines and professionals are involved in home care, their representation is relatively limited and the services that they deliver less essential in the daily lives of the older person. The HA is by far the most frequent and consistent caregiver to our community dwelling inner city, poor, old, sick citizens.

Many studies show that families caring for chronically ill relatives were suffering from stress related illness, job interruption, guilt, depression and marital discord. If families are experiencing economic and psychosocial hardship as a function of caring, it was likely that the formal caregiver, the Home Care Worker would likely have stress. This study advanced the thesis that home care workers, juggling the many roles of mother, worker and perhaps family care giver, would most likely be vulnerable to stress-related illness. Since only one study had focused on the HA herself, and since this occupation has grown to over 50,000 low wage workers, it was important to gain more knowledge about this relatively new occupation.

Robert Caplan and his colleagues studied the impact of job stress on the physical and mental health of workers in twenty-three occupations. He concluded that certain characteristics of working are associated with high levels of psychic strain: low participation in decision making, ambiguity about future job security, poor utilization of skills and abilities and lack of social supports from co-workers.[1] Given that each of the conditions that Caplan presents is built into the fabric and structure of the home care occupation it is not surprising that the incidence of stress related illnesses among these workers is, in some cases, close to twice that of the national average.

The findings presented in Chapter IV are quite revealing. The findings fly in the face of the inaccurate and demeaning stereotypes about the working poor women who comprise this workforce. By all standards the women who are the cornerstone of the home care industry are poor despite their work, despite their benefit to the functionally disabled community dwelling older citizens of New York and their families. Their poverty is not due to irresponsibility or lack of commitment to the work ethic.

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[1] Donovan, R., "Stress in the Workplace." Ibid., 261.

There has been a raging national debate over the causes of poverty, with some people attributing poverty to individual flaws. Others, including most social workers, see the fault in the social and economic structure of the society. They are not "dependent outsiders." They are not poor due to "indulgence, vice or temperance." They are not "morally corrupt." Their economic enslavement is "beyond their individual control."[2] They are poor as a built in condition of their employment. They are poor "because secondary-sector jobs (low paying, low status jobs) offer almost no opportunity for advancement, the dual labor market reinforces the subordinated position of the ghetto worker."[3]

All funding for Medicaid in home care, by definition, comes out of Medicaid Federal, State and City monies. When the amount of money saved by the government in providing home care rather than institutional care is not reflected in wages, exploitation of the worker is the by-product. When workers are eligible or near eligible for a public benefit that is below the poverty level by design, an alternative definition of home care could easily be understood as a form of workfare, "forcing women with young children into the workforce."[4] It gives participants neither the skill

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[2] Katz, D. Ibid., 14.

[3] Ibid., 59.

[4] Ibid., 53.

training, wages nor job opportunities necessary to lift them out of poverty nor does it address the poverty of their children."[5]

This study is a stark statement about formal caregivers. The work lives of Home Care workers lack incentives, access, job opportunity and equity and are antithetical to the American dream. One must wonder not only why they continue to do their work, but how they remain on the job for years. The fact that they are a stable workforce is particularly remarkable given that the review of the literature indicates that nurse's aides in hospitals and nursing homes have a high turnover. One can speculate that these women work as Home Care workers, in part, because of some internal strength and motivation. That is to say, they are motivated to work in the health care industry out of a positive cultural, familial and/or spiritual conviction about themselves.

The results of this study refute prior misconceptions about this cohort. They emerge as hard working women, who remain on the job for reasonably long periods of time, many of whom do not apply for public benefits, despite their eligibility. While the study did not tap motivation, the question of why they do what they do remains an area for future inquiry. One can only speculate that perhaps these

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[5] Ibid., 228

women accept the social mandate to be care givers, and/or reject the humiliation inherent in application and/or receiving public benefits.

RACE, GENDER, POVERTY AND HEALTH

It was posited that while the HA represented a unique and growing occupational arena within the health care industry she was but one sub-group of a larger group of minority women employed yet living in poverty. This is only too true: according to the National Commission on Working Women, "80% of women in the work force are employed in low skilled, low wage jobs."[6]

One question raised by this study is: how can we account for the paradox of women's working resulting in their continued impoverishment? Katz, citing Joan Smith's essay, "The Paradox of Women's Poverty: Wage Earning Women and Economic Transformation", attempts an explanation.

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[6] Lefkowitz, R. & Withorn, A., Ibid., 16.

> "The feminization of poverty has two sources: the increased number of female headed households and the kind of work women do. Women work primarily in the service sector, whose explosive growth accounts for most of the jobs open to them. Most of these jobs pay low wages..., increasingly they are part-time, and they less often carry health insurance or other fringe benefits. In fact, the business environment in the service sector has two key characteristics: a low capital-to-labor ration and frantic competition. This means that the service sector industries strive to increase the size of their labor force and to decrease wages they pay. In other words, they want lots of cheap labor. Women, willing to work part time for low wages and no benefits, provide the major labor pool. As a consequence, service sector jobs pay less than a family wage and women who work in them but lack other sources or income to remain independent of parents husbands or government supports...As a result, women's poverty and continued dependence remain central to the most rapidly expanding sector of the American economy."[7]

There is ample documentation that a marginal economic condition has multiple negative consequences. "We know that economic disadvantage is associated with health disadvantage... poor people are likely to face frequent illness because of poor living conditions, high levels of stress and reduced access to health care. Then, when they get sick and

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[7] Katz, D. Ibid., 74.

miss work or lose jobs, they are likely to become even poorer."[8]

The results of an unstable economic base compounded by inadequate benefits and resources impact not only on the individual but on the work force as well. Furthermore, unnecessary stress is placed on the government since workers must rely on residual entitlements rather than on institutionalized employer-provided benefits. When "more than three quarters of the poor in this country are women and children"[9] one must wonder about the values and policies that allow and perpetuate this condition.

We know only too well that "minority women suffer disproportionately from discrimination, social prejudice, stereotyping and unequal access to education and employment opportunities. Such inequities directly or indirectly impact on their socio-economic status and quality of life. In turn, these affect their health status. Faced with so many obstacles, it is not surprising that minority women bear a disproportionate share of diseases."[10] The high incidence

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[8] Gentry, H. "Women's Health - A Cause For Action: Social Factors Affecting Women's Health," Public Health Reports (July-August 1987) Supplement: 8-9.

[9] Ibid., 9

[10] Lin-Fu, "Special Health Concerns of Ethnic Minority Women." Public Health Reports. (July-August 1987): 14-17.

of hypertension, cardiovascular disease, diabetes and cancer among Black women can be related to their historical role and economic stress of their employment. Indeed, it is hard to believe that the "economic devaluation and marginalization of women"[11] has been beneficial to working women, their children, the workforce or to society.

The link between income and health is an unfortunate and undeniable reality. The National Health Interview Survey[12] found that of the people aged 25-44, who earned under $10,000 annually, 19.4 percent reported their health to be fair to poor. Of the same age group earning more than $35,000 a year, only 2.9 percent reported fair to poor health. Put another way, poor people report fair to poor health six times more often than those with adequate incomes. The statistical difference becomes even more remarkable for the age cohort 45-64 years old. A full 50.5 percent of the poor rate their health as fair to poor, compared with 6.9 percent who earn $35,000 and over. Economic well being is an indisputable significant factor in the self report of health status. Given that one third of the sample of home care workers have one chronic condition and another third had two or more stress related illnesses, the national survey provides validation for the findings of this study.

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11 Abramovitz, M. Regulating the Lives of Women. Boston: South End Press, 1988.

12 Adams, P.F., Ibid., 118.

Dr. Mimi Abramovitz, in her retrospective of working conditions of Black women living in the early 1800's, writes:

> Forced by dire poverty to work for wages outside the home, they (Black women) also faced severe exploitation on the job, having to accept the lowest wages, longest hours and most dangerous working conditions. On all fronts the families of poor and immigrant women and women of color experienced a series of assaults.[13]

Abramovitz, in describing conditions of Black women more than one hundred and fifty years ago, might also be describing the conditions of today's Home Attendants. She could also be describing the conditions of nurses aides, home health aides, foster parents, migrant workers, shelter care workers, mental health therapy aides, day care workers, to name a few occupations in which women of color work to help needy and dependent citizens and remain poor.

While the physical health of working poor and immigrant women and women of color is jeopardized, it ought to be pointed out that "poverty related deterioration"[14] represents costs to the health care system and society; costs rise as these exploitive conditions are perpetuated.

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13 Abramovitz, Ibid., 39.

14 New York Times, "Emergency Rooms Overwhelmed as New York's Poor Get Sicker." December 12, 1988; p. 4 (B).

The association between income and psychological disorder is well established. "Poverty has been found to be destructive to women's mental health" and has been identified as one of the priority areas of the Women's Research Agenda of the National Institute of Mental Health.[15]

According to the census, "for female-headed households in 1984 the poverty rate was 34.5 percent. The poverty rate for white female-headed households was 27.1 percent, for Black female-headed families 51.1 percent and for Hispanic families headed by women 53.4 percent."[16] Poverty is not necessarily the result of unemployment. Rather "the working poor were the fastest growing segment of the poverty population; 8.9 million in 1986, compared with 6.5 million in 1979. The number of full time, year-round workers who are poor has increased from 1.36 million in 1979 to two million in 1986."[17]

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[15] Amaro, H. & Russon, N. "Hispanic Women and Mental Health: an Overview of Contemporary Issues in Research and Practice." Psychology Of Women Quarterly 2, no. 4 (December 1985): 393-405.

[16] Sidel, R. Women & Children Last. New York: Penguin Books, 1987.

[17] New York Times, "Always With Us," November 19, 1987, p. 31 (A).

The women in this study are in triple jeopardy due to race, gender and poverty. They are another group, in the world of work, whose marginality relegates them to the underclass; jobs wherein the inadequacy of salary is compounded by inadequate health care, where poor working conditions are exacerbated by lack of career ladder.

Until HA's are given recognition of their rightful place on the health care team, it is likely that they will continue to be in jeopardy. Until women's work is afforded the same status as men's, occupations which are dominated by women workers will be areas ripe for exploitation. As long as "employed women in the United States earn about 70% of men's wages,"[18] the conditions of women workers will remain unjust.

THE FAMILY

As discussed in Chapter II, studies of family caregivers indicate that there are social, emotional and economic costs to caring for elderly relatives. Stress related illness, depression, guilt and marital discord have been documented as some of the negative consequences of caring for chronically ill older relatives.

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18 Scarr, S. Phillips, D. and McCartney, K. "Working Mothers and Their Families," American Psychologist, (November 1989): 2-14.

There is an inaccurate underlying assumption that if quality home care were provided, families would do less on behalf of their relatives. The myth that provision of formal supports will in some way diminish family contribution flies in the face of research facts. In fact, families turn to the formal system only when they have depleted their own resources. It is certainly difficult enough for a family to deal with the emotional pain of watching sickness, disfigurement and personality change in a loved one. Families deserve the assurance that their loved ones are being well cared for by workers.

The reality is that the projected needs of older people, and hence, their family caregivers, will only continue to grow and intensify. The need for older people to be cared for at home by paid workers is an undeniable fact of life. Caregivers need to have their caring supported by home care workers. The formal system of caregiving is not and will not supplant the informal system. It ought to be designed to support the family. Home care workers ought to be seen as friends of the family, however, under the present structure there is no pragmatic vehicle to mediate family expectations.

In a recent unpublished survey conducted while this author trained personnel specialists, they report that a major issue is the exploitation of home care workers by the

client's family, as well as elder abuse by family. It is a compelling assumption that home care workers are preventing abuse and providing relief to families, however more research is needed to asses how the family is specifically helped by the provision of home care services. The impact on families has not been systematically studied, despite anecdotal stories.

Families need to be counseled about negotiating systems, taught about rights and benefits and given an opportunity to mediate expectations with their caregiving counterparts, home care workers. Regardless of whether the home care worker is an employee of a vendor agency or hired privately, optimally families should be able to work with home attendants as surrogate family members who provide concrete and interpersonal care. Clearly, it will take ongoing work to help families achieve a working alliance with home care workers.

Public policy must focus attention on the needs of family caregivers. As families have become more mobile, they are less able to render the care that was afforded in the pre-industrial era. Furthermore, as family size has decreased, there are fewer adult children available to share the caregiving chores. As women have entered the labor force in increasing numbers, they have less discretionary time to devote to the care of older relatives. Home care workers

fill the void created by changes in socio-geographic and family composition. It is in the interests of all parties - the functionally disabled, the frail elderly, the family and the home care workers - to recognize the home attendant for what she is: the caregiver when the family has given all the care it can, and the person who helps the family to continue to care. To paraphrase Frank Caro, a primary purpose of community care is to decrease the unreasonable burdens placed on the caregiving family.[19]

Long term care ought to support the involvement of families through the provision of trained and well paid home care workers. Home care should be seen as a united effort wherein families and formal providers help older people to remain as they wish and in their own homes. Long term care translates into what society will provide to allow families to offer emotional and concrete supports that are within their means without becoming ill and overwhelmed themselves. Long term care should be understood as support not only for old people but tangible concrete chore services which will permit families of older people to continue on in their own lives, in their jobs and with their own children.

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[19] Caro, F. "Measuring Attainment," 7.

Nursing homes become an option only when a person can no longer be cared for in the community. Shanas[20] has established that eighty percent of all care to the elderly is rendered by families. Home care needs to be understood, as Caro has said, "as a support to family - to avoid unnecessary burden."[21] We need to conceptualize in home care to the elderly as a partnership between the formal and informal caregivers, between home care workers and family, including the home care client into the equation.

LONG TERM CARE POLICY

Every social indicator points to the need for further exploration of the social and economic aspects of long term care. This was documented in Chapter II which presented a demographic, economic, cultural and familial compilation of contemporary social gerontological facts and findings.

Two indisputable facts emerged from the literature: first, the ever increasing need for long term care; secondly, a projected increase of 64% among the aged 75 and over, by 1995. All demographic forecasts anticipate that the population of those in need of long term care will expand in

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20 Shanas, E., "The Family as a Social Support System in Old Age," The Gerontologist 23 (1983): 169-174.

21 Caro, "Measuring Attainment." Ibid.

absolute and proportionate numbers well into the next century. The second most significant fact is the psycho-social and economic pressures that are experienced by families. It should be noted that in any discussion of long term care policy consideration must be given to the central role of the family and the negative impact that providing long term caregiving can have on the providers.

ECONOMIC COSTS AND CONSEQUENCES

After focusing on the history of the development of federal long term care policy and describing the program structure of Medicare and Medicaid in chapter two, some economic and social facts need to be underscored: nursing home care is generally three times as expensive as in-home care. While the traditional formulation of the home care option has been to compare its cost efficiency to nursing home costs another means of comparison is costs of home care to its cost saving aspects vis-a-vis acute care hospitalization.

The findings indicate that in-home care saves money on acute care hospitalization. Brill and Horowitz[22] found that the average stay of those who receive home care is significantly less than for a control group. They found that

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22 Brill, R. & Horowitz, A. "The New York City Home Care Project: A Demonstration in Coordination of Health and Social Service." Home Health Care Quarterly 3, no. 4 (1983): 106.

the average hospital stay for home care program recipients was 17.3 days per year compared to 23.4 days for those without home care services. The six day savings multiplied by the many people who could benefit from in-home care suggests an enormous economic benefit in reducing acute care hospital costs.

Supporting Brill's finding is the work of Kramer, et. al.[23] They found that while Medicare nursing home and home health patients have relatively similar long term care problems in terms of cost effectiveness, home health care may provide a substitute for acute care hospital use at the end of a hospital stay. Home care, they suggest, may be a more viable option in the care of patients who are not severely disabled and do not have profound functional problems.

The overwhelming amount of Medicaid funded long term care is paying for the five percent of the aged in nursing home care. The economic facts of the fiscal benefits of home care are clear. The United Hospital study of 1984[24] comparing the costs of publicly financed long term care revealed that $1.4 billion dollars was spent on the 36,072

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23 Kramer, A., Shaughnessy, P., Pettigrew, M., "Cost Effectiveness Implications Based on a Comparison of Nursing Home and Home Health Case Mix." Health Service Research 2, no. 34. (1985): 387-405.

24 United Hospital Fund Study, Ibid.

patients in nursing homes compared with the $500 million spent for the care of 59,554 home care patients. "The cost of extensive home care is estimated to be one third that of nursing homes, which averages $40,000 a year in New York City.[25] However, the costs clearly vary depending on the clients' needs, which in some cases can exceed nursing home costs.

Nationally, home care services, "a $7 billion dollar a year industry is expected to expand to $18 billion by 1991."[26] The New York Times noted[27] "...last year New York spent almost $2.1 billion on home health care, or roughly 80 percent of all the Medicaid dollars in the country devoted to such care." Steele[28] found that while costs for those over 65 are many times the per capita costs of younger Health Maintenance Organization enrollees, these costs may be significantly less than the costs of institutional care. However, while on an individual basis home care is a far less expensive alternative to nursing homes care, given that more

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25 New York Times, "New York Shifts Care of the Elderly to Their Homes." May 4, 1987 p. 1 (A)

26 Ibid.

27 New York Times, "New York Medicaid: Costs Surge, But Care For Poor Still Lags," April 14, 1991, p. 24 (A)

28 Steele, K., et. al. "An Analysis of Type and Costs of Health Care Services Provided to an Elderly Inner-City Population," Med Care, 20, no. 11 (November 1982): 1090-1100.

and more people will need home care, the absolute rather than proportional costs may in fact prove quite costly. The economic argument in favor of home care cannot be seen as the most pivotal aspect of the policy debate. The argument in support of in-home care is based on humane values that have been the trend for the last twenty-five years. Furthermore, in home care is a more appropriate level of care for most old people who neither want nor need institutionalization.

SOCIAL COSTS AND CONSEQUENCES

Deinstitutionalization has been the national policy of choice since the mid 1960's. It is based on social and economic considerations as well as on ideological assumptions. The community care of the retarded, the mentally ill, foster children, therapeutic communities and the elderly provide ample evidence that in addition to perceived economic benefits to society, there is an underlying ideology that values the provision of service in the community. The home rather than the institution becomes the site for service delivery. While there have been some negative social consequences to deinstitutionalization of the mentally ill, home care remains an area where there generally is agreement between client, family and policy. While the challenge to national policy makers is to provide cost effective and comprehensive health care to the elderly, we must also recognize the social costs and consequences to the elderly

themselves. McAuley,[29] et. al., found that for both rural and urban respondents the most frequently selected long term care options were those which allowed the individual to receive assistance at home.

It is a well known psycho-social fact that the more people can exercise options the more they feel a sense of mastery and power over their environment. The increased provision of the preferred home care option as an alternative to institutions care can only result in psychological benefits for older people. Preliminary reports indicate that in addition to being the service of choice of older people, home care may also aid in more rapid recovery. Currie, et.al.[30] found that 28 of 37 patients made satisfactory functional recoveries at home. Their preliminary evidence suggests that in patients with comparable illness recovery of function in terms of Activities of Daily Living is more rapid at home than in hospital when provided with augmented home care services.

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[29] McAuley, W., Blieszner, R. "A Comparison of Rural and Urban Elderly's Expressed Preferences for Long Term Care Arrangements." Rural Sociological Conference. Virginia Polytechnic Institute Gerontology Center., 1985.

[30] Currie, C.T., et. al. "A Scheme of Augmented Home Care for Acutely and Sub-Acutely Ill Elderly Patients: Report on Pilot Study." Aging 9, no. 3 (August 1980): 173-178.

Long term care policy in the United States is that policy which will determine the options available to our older frail citizens. When we talk of long term care we speak not so much of an abstract policy than we speak of how we provide for one of our most vulnerable populations, people who are old and frail and sick and who are often members of our families.

It is important to recognize that the domain of in-home care is not exclusively an issue of the aged. While currently the vast majority of home care clients are elderly, those eligible for publicly funded in-home care include functionally disabled children and adults, some of whom are crack addicted children and people with Auto Immune Deficiencies.

MEDICARE

Policy and provision differ depending on which of the two federal options is being considered. Medicare, the universal health coverage to the aged, blind and disabled, is an acute care coverage. Somers and Somers[31] show that the primary intent and function of Medicare legislation was to offset the costs of in-hospital stays. While it serves this purpose, other than limited outpatient coverage, Medicare was not intended (nor should it be construed) as a reliable and

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[31] Somers and Somers, Ibid.

ongoing source of long term care. The home care provision of Medicare is an acute care benefit that covers only those conditions from which one can recuperate.

The fact is that the majority of illnesses that older people have are chronic conditions, requiring ongoing and consistent care. While Medicare serves an important function, not the least of which is helping to keep hospitals solvent, in fact Medicare is not insurance for long term illnesses requiring ongoing nursing or in-home care. It is short term, acute care for conditions from which one can recuperate either at home or in brief nursing home stays. Therefore, when we talk about the provision of publicly funded long term care we are truly talking exclusively about Medicaid's provision in some states.

MEDICAID

Medicaid, title XIX of the Social Security Act, is categorical, need-based social health insurance. Eligibility for Medicaid is synonymous with pauperism insofar as the income eligibility levels are so remarkably low that only those with the most meager incomes well below the poverty line, and who have very limited assets are eligible. Those elderly who have historically been poor are likely to qualify, provided that they are willing and able to apply and/or assisted with an application process which builds in barriers and disincentives.

The middle class and the rich can qualify for Medicaid under two conditions: they must transfer their assets two years prior to application, or they can "spend down", using their monies for their medical and other needs until they have divested themselves to the point of impoverishment. Given that the average cost of nursing home care is currently estimated to be $40,000 a year, older people must choose to dissipate all that they have gained by their labor and careful living in order to pay for their care. They are deprived of passing on the economic legacy that has been a customary middle class practice.

In any event, Medicaid funded long term care translates into two options: institutionalization or in-home care. While nursing homes serve a useful medical function, they are just that; places in which old people receive the care of nurses, aides, physicians, social workers and other therapeutic disciplines, because they are medically unable to attend to their own needs. They are very sick and very old. The average age of the nursing home resident is 87 years. As the population has grayed it has become more difficult to qualify for admission into nursing homes. Note the relatively recent emergence of the Review Utilization of Geriatric Services (RUGS) which serves to closely screen eligibility for nursing home admission.

The broadest long term care option, and the one empirically documented to be preferred by the old, their families and society, is the community based option, Medicaid funded in-home care. Certainly home care programs are not without their problems, not the least of which is the lack of training and supervision of the workers, however, given the current public policy options it is the most viable long term care option in New York State. It is safe to predict that barring any new federal policy initiatives, Medicaid funded in-home care will become the wave of the future; more and more states will adopt the home care as the only feasible alternative for attending to the social health care needs of the frail elderly.

In New York City, the service delivery mechanism for the provision of Medicaid funded home care consists of the home attendant vendor programs which are subcontracted by the City. As was discussed in Chapter III, these are small, usually single purpose agencies. They are dependent on the City for funding and committed to the coordination of home care clients with home care workers.

UNIONIZATION

It is clear that the unionization of this growing cohort of workers has been pivotal in providing them with a power base and source of advocacy. Without the union as an organizing institution, these women would be individual

workers, without a voice, without protection, without a source for grievances or labor negotiations. It is also likely that without the union this study could not have been conducted. The HA's represent the newest and single largest cohort of the union. It is in the interests of Local 1199 leadership to show the benefits of that leadership to its membership.

"As a result of a major combined union-agency organizing and public relations campaign home attendants in the New York City Human Resources Administration Home Care Services Program won a significant increase in wages and benefits in 1987."[32]

It was anticipated that the Member Assistance Program for Local 1199 Home Attendants, developed soon after Dr. Donovan's study was completed, would continue to be a helpful and necessary resource for Home Attendants. Not only has the program continued but it remains supported by the union through the continuation of stipends for two Hunter College School of Social work interns, retention of Carol Rotman as its social work director and increased utilization. While it was assumed that the women in the sample would be more likely to use the services of the MAP as a consequence of the researcher's encouragement and information provided

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[32] Surpin, R. & Grumm, Ibid.

during the data collection, statistics on utilization for the sample are unobtainable.

RECOMMENDATIONS

The recommendations to be advanced are based on Lewis'[33] conceptualization of principles of practice. Lewis defines principles of practice as being guided by two elements that comprise ethical imperatives: oughts and shoulds plus knowledge. In order for the findings presented in chapter IV to have importance beyond the immediate information it provided, it is necessary to make recommendations that will impact practice and policy. The recommendations to follow, while grounded in the findings, go beyond the findings by expanding comments into all levels of long term in home care. These recommendations are grounded in values that represent the basic justification of our profession: positive change to allow more citizens to live healthier and more fulfilled lives. In social work our beliefs must be impassioned with the conviction that our work has positive, humane, just, and moral impact; it advances the goals of a civilized society by maximizing alternatives.

Efforts should be made to offer part time workers full time work. Since 64 percent of the part time workers want and need more income and since part time workers are

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[33] Lewis, H. The Intellectual Base of Social Work Practice. Ibid.

excluded from any health benefits as a condition of their employment, efforts should be made to expand part time jobs into full time jobs. Rather than expand the staff with part time workers, attempts ought to be made to create additional full time positions. This requires that the personnel specialists, those first line managers who hire workers and coordinate assignments, keep a careful registry of workers, giving special emphasis to the quality of worker performance. Systematic evaluation of worker performance builds in a much needed reward system for the part time workers who want to become full time employees.

The needs of individual workers ought to be considered vis-a-vis geographical location. The regression analysis showed that there was a significant relationship between commuting out of borough and the prevalence of stress related illness. Perhaps, through the Home Care Council, the federation of vendor agencies, out of borough workers would be referred to vendor agencies in their home borough as openings arise. In addition to the possibility of lessening the incidence of SRI's another beneficial offshoot of the mutual referral network would be a greater cohesion among interagency personnel.

The union ought to evaluate the member assistance program, now in its fifth year, to see the nature of the

workers' needs, to see if there is a pattern to the particular kinds of help they seek. Such an evaluation would help in determining if systemic problems within the workplace can be addressed.

Given that half of these women are high school graduates, the union ought to exert political influence in order to create a means of supporting educational opportunities. The goal of converting dead end jobs into entry level jobs becomes a reality when home care workers can advance to Licensed Practical Nurses, respiratory, intravenous and recreational therapists, etc. However, like physician's assistants, the position itself ought to be given more dignity. Opportunity ought to exist for advancement within the status of home care worker. It is reasonable that some link be created between public community colleges and community centers. In the way in which Hunter College School of Social Work - the only public school of social work in new York City - has created cooperative educational programs for employees of the City's Human Resources Administration, so, too, the creation of educational opportunities between Local 1199 and community colleges offering health career curricula is an avenue for exploration. The cooperative efforts of Hunter College School of Social Work, Local 1199, The Home Care Council and officials of the City's Home Care Services Program might develop a creative solution to the building in of career ladders for home care workers.

For the fifty percent of the women without high school diplomas the union's MAP could explore local high school offering general education diplomas (GED's) and/or consider union sponsorship of GED programs.

The literature review on the definition of the home care worker presented two points of view. One school of thought argued for seeing home care workers as primarily chore service providers. Another school of thought recommends professionalization of the occupation. It ought to recognize that while some regard this group as glorified servants, in fact they are the fulfillment of a medically prescribed service. What is most outstanding about the results of the economic analysis is the extent to which the incomes of these women are in or near poverty level. While it is likely that increased training and supervision will allow for a greater professionalization of the workforce as well as make it more likely for home care workers to be able to earn a living wage, it is possible that greater requirements may displace some workers. Even if some workers are unable to meet more rigorous criteria, it is still worthwhile and the only responsible position one can take. The current mandate of six hours of training annually limits the opportunity to learn. It serves, somehow, to justify inadequate pay.

If we are committed to the provision of quality care we must recognize a number of gerontological facts related to home care. The client group served by home care workers is a demanding cohort. Their general characteristics are such that even highly trained and credentialed professionals must call upon sophisticated diagnostic, theoretical and technical skills in order to help these old people. They are sometimes depressed and/or organically compromised, sometimes paranoid, often physically ill, and functionally disabled. Compounding all of the foregoing, they often live alone and in poverty. It is unreasonable to expect that we insure quality service delivery when we deprive workers of training in the physical, emotional, social and cultural realities of the aged clients whom they serve.

To assure maximum effectiveness, it is important that the lines of communication be open between home care worker, personnel specialist, nurse and outside workers involved in case management. Case review conferences should be implemented, to monitor and assess the changing needs of clients. This recommendation is confirmed by the literature review which found that the ability to have input into cases was critical to the psychic rewards of direct care workers. Case reviews serve the function of quality assurance and enhanced worker morale.

This recommendation has precedents in the foster care system, in which foster parents, seen as an arm of the agency, have regular and ongoing meetings with foster care workers and supervisors.

On a broader scale, the home care worker ought to have parity with her counterpart in institutions, hospitals and nursing homes. While historically there has been a salary differential between community-based workers and those employed in health care institutions, this lack of equity is not grounded in the demands of the job. Primary care of people has always been devalued and home health workers suffer from that prejudice. Parity between direct care home care workers and nurses aides would allow for the much needed raise in wages and benefits. It should be noted that about 90 percent of personnel providing direct care in nursing homes are untrained.[34]

Along these lines, there is an infinite variety of ways of helping home care work become entry level rather than dead end jobs. It is possible to have, for instance, as two year period of community work as a prerequisite for a job as a nursing assistant. Tangible rewards are then built into consistent and quality service delivery. In the way in which

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[34] Minkler, N. "Health Promotion in Long Term Care: A Contradiction in Terms." Health Education Quarterly 2, no. 1 (Spring 1984): 77-89.

most schools of social work require demonstration of direct experience in the field as one criteria for admission into graduate training, so, too, the more well paid and secure, less isolated in-hospital job could be made the next step on the health care career ladder for home care workers. Local 1199 represents community agencies as well as voluntary hospitals and nursing homes. It is reasonable for the union, in its representation of home care workers, to advance the proposal that as institutionally based jobs become available those jobs are offered to home attendants as a reward for a job well done.

In the best of all possible worlds, genuine parity would allow not only for equal pay whether in the community or in the hospital, but for a career flexibility wherein institutional workers could opt to transfer into community home care and vice versa. The author has met numerous registered nurses who have left the hospital setting for community-based home care work.

The need for affordable day care is without doubt a national concern and, not surprisingly, one shared by the women who pay for day care while they do day work! Many corporations in the private sector, realizing the benefits of maintaining a stable workforce, have developed on-site day care centers as a benefit for their employees. Vendor agen-

cies with settlement house affiliations and/or vendor agencies which are a part of their communities ought to consider expanding their programs to include day care programs which would have openings for the children of the home care workers. Vendor agencies ought to explore existing day care resources and/or create programs for the children of their employees.

Health care benefit packages ought to be expanded to include family coverage. The investment in accepting additional costs in the short run will likely avert greater economic, labor and health costs in the future.

CONCLUSION

In the way in which home care workers are but one segment of the working poor women of America, the elderly are but one segment of society for whom home care is a necessity For the parents of functionally disabled children - those with severe palsy, muscular dystrophy, cystic fibrosis, schizophrenia, severe birth defects and retardation - the parents' decision to maintain the child in the home is one heavily dependent on constant caregiving. The psycho-social and economic burdens associated with the decision to maintain a family member are quite real, whether they be young, old, disabled, and/or outside of institutions. If we are to support the will of the people to maintain their families, we

must, as a society, support and expand our commitment to community based programs and services.

By definition and by design, nursing homes are the port of last resort. It is beyond the scope of this paper to describe and analyze the many limitations of institutional care. Suffice it to say that it is with the greatest reluctance that families of all cultures seek institutionalization for their loved ones. As a society we ought to provide adequate and accessible formal options to citizens in their attempts to avoid the more costly, less preferred, often less therapeutic alternatives.

The in-home care option of services is the direction of future provision of psycho-social health care. The quality of that care deserves to be assured so that people are freed from the additional and unfortunate stresses associated with the adult obligation of caring for our loved ones. Investing in the training, supervision, career path and career ladder, and wage and health benefits to home care workers is an important investment in the quality of life for families.

EPILOGUE

While the conceptualization for this study was completed in 1983, the process of implementation and data collection (described in chapter three) occurred in 1987. In the ensuing five years several significant studies, events and policy suggestions have emerged. This epilogue will review the significant recent publications in order to update the state of the knowledge, with an eye toward the year 2,000.

It is a joy that this new material has been produced since one of the overall goals of "Friends of the Family" was to focus greater attention on the growing arena of community-based, publicly funded long term care.

The Pepper Commission,[1] a bi-partisan federal initiative, which will be reviewed in this text, attests to a growing national awareness; home care is by no means a local policy issue. Rather, it is the need for the federal government to plan policy on behalf of elderly and disabled citizens and their families which will ensure adequate in-home services and protection from pauperization. It is an item

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[1] United States Congress, Senate Committee on Labor and Human Resources. A Call For Action: Pepper Commission Recommendation on Universal Health Care. 101st Congress, 2nd Session. 1990, S. Hrg., 101-859.

that will assume greater priority on the national agency for years to come.

Likewise, Donovan's 1991[2] follow-up study, Cantor,[3] Quinlan,[4] Surpin,[5] and Feldman's[6] work all add to clarifying the direction for the personnel who staff existing programs.

The Pepper Commission found that "between 9 million and 11 million Americans of all ages are chronically disabled, dependent on others for help in basic tasks of daily living that we call 'long term care'".[7] The cost to the nation was $53 billion in 1988. However, "only 18 percent of these expenditures went to home care--despite the fact that

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2 Donovan, R., and Rotman, C., "The Health and Social Needs of Home Care Workers." March, 1991. TMs.

3 Cantor, M., Stress and Strain Among Home Care Workers of the Frail Elderly. Brookdale Research Institute on Aging. Third Age Center, Fordham University, June 1990.

4 Quinlan, A., "Chronic Care Workers: Crisis Among Paid Caregivers of the Elderly." Older Women's League & American Federation of State, County and Municipal Employees, AFL-CIO. 1988.

5 Surpin, R. and Grumm, F., Ibid.

6 Feldman, P.H., Who Cares for Them? Workers in the Home Care Industry. Westport, CT: Greenwood Press, 1990.

7 Pepper, Ibid., 10.

four out of five disabled and almost three out of five severely disabled live at home." [8]

One suggested strategy for coping with the anticipated 14 million elderly who will need help by the year 2030 is "the development of a comprehensive public insurance program for all long term care services."[9]

While Cantor recommends "some mechanism at funding home care for the vast majority of older and disabled persons that does not pauperize them...",[10] the Pepper Commission goes a step further. "The Commission believes that federal social insurance for home and community based care is essential to ensure the development of an adequate and efficient delivery system for these services and that priority in the use of public resources should go to disabled people at home or able to come home after short nursing home stays...regardless of income."[11]

If the proposed program were in place in 1990, 4.4 million people would be served costing the federal government $42.2 billion, $24 billion of which would be for care at

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[8] Ibid. 11.

[9] Ibid., 14.

[10] Cantor, Ibid., 58.

[11] Pepper, Ibid., 16.

home. Yet, "the nation would have a system to which everyone in need could turn for help."[12]

In 1991 Donovan[13] did a follow-up study of her initial demographic profile of Local 1199 home care workers. While most of the demographics of her New York City sample remain consistent with her initial study and similar to this and Cantor's study, her 1991 study showed some findings worth reviewing.

There has been a 10 percent increase in the employment of foreign born workers. Given that there has been an increase in the need for service and the history of home care workers as primarily immigrant and minority women, this finding is not surprising.

The economic profile of the workers has, however, changed in the last five years. The median family income has risen from $8,000 annually in 1986 to $12,000 in 1991. While the cost of living and inflation have not been accounted for, clearly the contract negotiated by the union in 1988 is an unquestionable factor in the 33% increase in median salary. While these gains by the workers are noteworthy, it is impor-

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12 Ibid., 18.

13 Donovan, R. & Rotman, Ibid.

tant to recognize that a median annual salary of $12,000 for working mothers with children remains unacceptably low.

However, despite the rise in annual family income a comparison of Donovan's 1986 and 1991 findings along the dimension of severe economic hardships shows a consistency of hardship vis-a-vis affordability and adequacy of food, furniture, money, medical care and clothing.

There has been a 22% growth in the numbers of workers who are now covered by Local 1199 health insurance. This positive growth represents yet another direct benefit of the union contract. Yet the majority of workers incur out of pocket medical expenses they can ill afford. The number of women having trouble getting medical care has fortunately decreased from 61 percent to 36 percent. It is possible that the expanded and enhanced health benefits package, along with the union based Member Assistance Program, is responsible for this improved access to health care.

Medically, the incidence of hypertension and vision problems remain consistent over the years: 33-34 percent and 35 and 34 percent, respectively. The incidence of all other reported health problems has however declined: in 1986 foot problems were reported by 23 percent of the respondents as compared to 13 percent in 1991; asthma/allergies have declined from 33 percent to 18 percent; arthritis, from 22

percent to 18 percent; headaches are almost half as often reported (25 to 13 percent). While it is difficult to account for these changes other than through greater usage of insured medical services, clearly they are encouraging.

In the general arena of social problems experienced, results are worth noting. There has been a decline in reported health problems, from 29 percent to 16 percent, yet legal problems have more than doubled (12 to 25 percent). The need for child care has more than doubled (10-20 percent) and workers reported a dramatic rise in marital problems, from eight percent in 1986 to two percent in Donovan's more recent study. Housing problems remain the most frequently encountered, up from 44 percent to 60 percent. Given the housing shortage in New York City, it is not surprising that poor women with families experience this need.

Donovan's 1986 and 1991[14] studies found surprising stability in the work force. This is further confirmed by Cantor's and Unterbach's findings.

Job satisfaction has remained relatively unchanged in the last few years, however, fewer workers are very satisfied in 1991 (26 percent) as compared to 35 percent in 1986.

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14 Donovan & Rotman. Ibid.

One additional area of inquiry, hazardous working conditions, was explored in Donovan's more recent study. A full 72 percent of the home care workers studied reported an average of three to four hazardous working conditions. The two most common are unsafe/crime ridden neighborhoods (62 percent), drug infested buildings (55 percent). If workers are finding hazardous working conditions, it is a painful reality that the elderly and disabled for whom these workers work are living in these conditions! Forty-four percent reported incidents of home care worker abuse; some reported sexual harassment.

Cantor[15] studied the nature of the job related stress and strain experienced by home attendants and home health aides. While collecting data on demographics and work history, her focus was the degree of job related strain and job satisfaction. Given the conditions of employment known about the home care job, in addition to projects for its expansion, Cantor's study was a necessary and logical extension to the state of the knowledge.

Using a stratified random sample, Cantor studied seven home care agencies, including all the boroughs but Staten Island. Face to face interviews with 306 home attendants and 181 home health aides were conducted. Some of those findings are worth presenting.

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15 Cantor, M. Ibid.

It is an old administrative axiom that all jobs have costs and rewards. Maintaining a balance between the two results in the worker's contribution. One "recurring theme throughout Cantor's study was the significant worker attachment to these (client) relationships and to their 'family' role in enhancing the work situation, and, most importantly, the lives of the clients they serve."[16] Home care workers recognize the "tremendous importance of the socialization and emotional support they provide,"[17] which serves as an important psychic reward.

On the cost side of the equation, the highest area of job strain was, predictably, financial. As Cantor states, "the highest rate of financial strain in the case of home care workers is not surprising given the reality of the financial situation of so many of the low income home care workers studied."[18] This finding is evidence of the economic situation found by Unterbach. If this work force is to be retained and expanded some adequate floor of wages and benefits is essential.

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[16] Ibid., 16.

[17] Ibid., 24.

[18] Ibid., 35.

Likewise, the "overwhelming perception of the workers that the homecare job leads nowhere and offers no opportunity"[19] is another job related stress. Feldman states that "besides pay and benefits, other sources of dissatisfaction were the weekly work schedule, lack of opportunity for advancement, inadequate training and loneliness on the job."[20]

This "dead end" job must be reconceptualized as an entry level job. Since virtually everyone in Cantor's study said that pay and fringe benefits were inadequate, and that they saw no chance for promotion - a career ladder - remains an unequivocal fact. A career ladder specifying differential tasks, training skills, and pay differentials commensurate with increased responsibilities "could go a long way toward rationalizing the industry, providing workers with a real stake in home care and clients with improved service.[21] Cantor supports Unterbach's recommendation of an expanded career ladder through the use of "community colleges, ...university-based schools of public health and social work, as well as gerontological centers..."[22] To this end,

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19 Ibid., 41.

20 Feldman, Ibid.

21 Cantor, Ibid., 20.

22 Ibid., 52.

"states and localities could approve across the board increases in publicly funded home care programs to make wage and benefit packages competitive with those in nursing homes and hospitals."[23]

While the samples for Donovan's, Cantor's and Unterbach's studies were drawn from one New York City cohort of home attendants, the findings do not appear to be local. On a national level, a "1987 survey of home health agencies in five metropolitan areas (Boston, Milwaukee, New York City, San Diego and Syracuse) generated the same general profile: "95 percent female; average age, 45; 57 percent single and 60 percent primary providers, disproportionately Black...and Hispanic; average schooling, 11.7 years; average wages, $4.41 per hour. Over 75 percent earned less than $10,000 annually; few had employer provided health insurance."[24]

More opportunities to interact with other workers in group meetings as well as more "face to face contact with supervisors could help minimize the sense of isolation"[25] as well as enhance their sense of self as part of the social health team.

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23 Feldman, 206.

24 Quinlan, Ibid., 16.

25 Ibid., 40.

Year 'round salaried employment "would appear warranted both for the welfare of the workers and the stability of the industry."[26]

Like the Unterbach study, Cantor's study was completed prior "to the institution of the 1988 union contract. That contract provided somewhat higher hourly rates and better health coverage."[27] While "over 80 percent of the respondents" agreed that the union representatives were available when needed, interested in the workers' well being, kept the workers informed about occurrences, and offered workers help when needed, with personal problems"[28] Feldman offers an interesting perspective on the union's position. She states that "while the unions are the contract negotiators, "the City and State...determine the final outcome of negotiations by establishing the reimbursement rate to agencies."[29] In essence, while the union has played a very significant and beneficial role in the lives of these workers, its role must be viewed within the superimposed limits of existing governmental constraint.

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[26] Ibid., 47.

[27] Cantor, Ibid., 26.

[28] Cantor, Ibid., 33.

[29] Feldman, Ibid., 105.

The New York City Home Care Working Group, a coalition of vendor executives, representatives of the City's Human Resources Administration, Local 1199 of the Drug, Hospital and Health Care Employees Union, and social work academicians echo the findings of the heretofore mentioned studies. "Paraprofessionals require adequate income and benefits, job stability, decent working conditions and opportunity for advancement."[30] The degree of agreement between the various representatives of institutions cannot be ignored. Rarely is there such concordance on policy proposals among diverse groups.

Likewise the need for parity with other health care providers is "a major recommendation of the New York State Labor-Health Industry Task Force on Health Personnel, a group established by the New York State Department of Health."[31]

Surpin and Grumm conducted group interviews with home care clients and home care workers. Like Cantor, they found that one of the rewards of the job for the homecare worker is the provision of important services. Additionally, "adequate wages, good benefits, job stability, adequate training, compatible clients and families, safe and clean

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30 Surpin & Grumm, Ibid., vi.

31 Ibid., x.

working conditions, recognition and respect from their clients and agency, communication and support from the agency and opportunity for upgrading"[32] are the general requirements for all health care workers.

Greater parity with other health care workers is more likely to be obtained through "a new uniform home care paraprofessional title."[33] The Home Care Aide is the generic working title "that would incorporate the current titles of home attendant, personal care aide, home health aide and homemaker."[34] A uniform Home Care Aide title would dramatically oversimplify a very confusing system...at the same time it would increase the entry level training for most paraprofessionals in the field."[35]

The future is clear. "By the year 2000 the number of Home Health Aide jobs will increase by 80 percent, primarily because of the growing elderly population and the continuing trend to provide medical care outside the hospital setting."[36]

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32 Ibid., 28.

33 Ibid., 41.

34 Ibid., 41.

35 Ibid., 44.

36 Ibid., 7.

The jury has returned. The evidence is conclusive. The nation must plan for the demographic changes which will come with the new century.

We must plan to guarantee all citizens who become aged, infirm, and/or disabled affordable and adequate in-home services. The Pepper Report is a hopeful beginning. Donovan, Cantor, Surpin, Feldman, Quinlan and Unterbach have provided the evidence. We must recognize the knowledge gained from these studies and bring it to the attention of the public and our government.

Summary of Recommendations:

- Year 'round salaried employment
- Expanded career ladder
- Access to community colleges, schools of public health and social work.
- Continuation of the Member Assistance Program.
- Adequate income and benefits
- Decent working conditions
- Parity with other health care providers
- Generic home care title
- More face to face individual and group supervision.

Welfare vs. work

Woman with two children, one too young for school, living on public assistance

Monthly income

Woman with two school-age children who works as a cleaning woman in a nursing home

Monthly income

"I'm always running out before the end of the month, and I have to borrow from my neighbor to buy milk for the baby. If I drink enough coffee, I lose my appetite for a while."

[illegible]	[illegible]
[illegible]	[illegible]
[illegible]	[illegible]
[illegible]	[illegible]
[illegible]	[illegible]
	$[illegible]24

Woman with two school-age children who works as a cleaning woman in a nursing home

Monthly income	
[illegible]	$[illegible]
[illegible]	[illegible]
	$[illegible]

Expenses	
[illegible]	$[illegible]
[illegible]	[illegible]
[illegible]	[illegible]
[illegible]	[illegible]
[illegible]	[illegible]
[illegible]	[illegible]
[illegible]	[illegible]
[illegible]	[illegible]
[illegible]	[illegible]
	$[illegible]71

"The utility bills are always more, but as long as I pay something they usually don't shut them off."

APPENDIX B

LOCAL 1199
Drug Hospital and
Health Care Employees
Union RWDSU-AFL CIO

310 West 43rd Street
New York N.Y. 10036
(212) 582 1890

March 9, 1987

Dear Agency Executive

I am writing to you at this time to request your cooperation in allowing Dee Unterbach to administer her health and work questionaire to some of your home attendant staff.

Mrs. Unterbach has worked along with 1199 for over 3 years now and was helpful in the establishment of the Social Service Program that we developed.

We trust that the results of her survey will be helpfull in our shared goal of improved medical benefits.

She has our full endorsement in her efforts and we hope that you will permit her some of your in-service time.

Thank you in advance for your kind cooperation.

Very truly yours,

Aida Garcia

AIDA GARCIA, VICE PRESIDENT

AG:idl

Georgianna Johnson President
Edward Kay Secretary Treasurer
Katherine Abelson Executive Vice President
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APPENDIX C

HOME CARE SERVICES FOR INDEPENDENT LIVING, INC
1351 FLATBUSH AVENUE BROOKLYN NEW YORK 11210

(718) 282 0300

April 3, 1987

Dear Colleague:

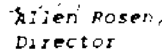
I have known Dee Unterbeck for the past three years in her professional capacity as a staff member of the Brookdale Center for the Aging.

She has always been interested in Home Care and is presently studying for her Doctorate.

As part of her dissertation, she is asking our help in asking Home Attendants to fill out a brief survey about their needs.

Our agency will participate in this study and I urge you to consider doing so also.

Yours truly,



Allen Rosen,
Director

:gg

APPENDIX D

May 20, 1987

Ms. Adeena Besdin
The Caring Neighbor, Inc.
331 East 70th Street
New York, N.Y. 10021

Dear Ms. Besdin:

As you may have learned from Allen Rosen, Hunter College School of Social Work recently completed a research survey to assess the health and social needs of Home Care Workers. One result of this study was the establishment of the first personal service program for Home Care Workers. This program, based at 1199, is the first of its kind. Hopefully, it will provide some relief to your Personnel Specialists, who may now refer Home Care Workers there who appear to be having problems that affect their work.

At this time I am conducting a follow-up study, focusing on the medical conditions and health benefits that Home Care Workers have. Our hope is that this survey will be a source of additional information for the Home Care Council, as well as add to the knowledge on the needs of the Home Care Workers.

I have written to request permission to administer a 15 minute confidential questionnaire to members of your staff either before or after a regularly scheduled in-service training session. Your agency was selected by random as were 11 other member agencies of the Council, to assure that findings would reflect needs in general.

Enclosed please find a letter of endorsement from Aida Garcia, Vice President of the Home Care Division of Local 1199, and from Allen Rosen of the Home Care Council.

Sincerely,

(Ms.) Dee Unterbach
Hunter College
School of Social Work

encl.

APPENDIX E

CONFIDENTIAL QUESTIONNAIRE

SURVEY OF THE HEALTH CARE NEEDS OF HOME CARE WORKERS

A. Marital Status:

1. Married _____
2. Separated or Divorced _____
3. Single-Never Married _____
4. Widowed _____

B. How old are you? ____

C. Do you have children?

1. Yes _____
2. No _____

D. If yes: How old are your children. (List ages of each child)

D.1 If you have a child(ren) under 6 years old, who care for your child while you work?

1. Day care center
2. Relative
3. Friend
4. Neighbor
5. Other, please specify ______________________________

D.2. About how much do you pay for child care each month? ____

D.3. What is your monthly rent? ______________________________

E. What country were you born in? ____________________

E.1 What borough do you work in?

1. Brooklyn ______
2. Queens ______
3. Manhattan ______
4. Bronx ______
5. Staten Island ______

E.2. What borough do you live in?

1. Brooklyn ______
2. Queens ______
3. Manhattan ______
4. Bronx ______
5. Staten Island ______

APPENDIX F

TO BE READ TO HOME CARE WORKERS BEFORE THE ADMINISTRATION OF THE HUNTER QUESTIONNAIRE

Hunter College School of Social Work is doing a study to find out more about your lives, your health and the health of your family.

The union, 1199, has given it's permission for you to participate and so has this agency.

We all hope that by knowing more about HOME CARE WORKERS, as a group, wemight be more able to help you with your own needs and concerns.

There is a FREE social work service located at the union, on 43 Street, in Manhattan. If you are interested in getting help that is confidential please feel free to call: 212-582-1890
and ask for Carol Rotman, MSW on the 6th floor.
Now please take about 15 minutes to fill out this confidential questionnaire.
Raise your hands if you have any questions.
Thank you

F. Did you complete high school?

1. Yes ____
2. No ____

G. How many months or years have you worked as a home care worker?

H. Do you currently work full time?

1. Yes ____
2. No ____

I. If you work part-time, about how many hours per week?-___

J. Would you prefer to work full time?

1. Yes ____
2. No ____
3. Unsure ____

K. Are you the only wage earner of your household?

1. Yes ____
2. No ____

L. How much money do you take home every 2 weeks? ____________

L1. Counting the money that everyone in your household brings home, how much money comes into your household every two weeks.

Now, we would like to ask you about your health, health care coverage and health care needs.

M. Do you know what your agency health insurance covers?

1. Yes ____
2. No ____
3. Unsure ____

N. Other than your agency coverage, do you have other medical coverage?

1. Yes ____
2. No ____
3. Unsure ____

O. If yes, do you have: Medicaid 1. Yes ____ 2. No ____
Medicare 3. Yes ____ 4. No ____
coverage from a husband or other family member 5. Yes ____ 6. No ____

P. Are your children covered by:
Medicaid 1. Yes ____ 2. No ____
Medicare 3. Yes ____ 4. No ____

Q. Where do you usually go for your medical services?:

1. Private doctor ____
2. Hospital ____
3. Clinic/HMO ____
4. Other (specify) ________________

R. In 1986, about how much money did you pay out of your own pocket for doctors, dentists and medicines, for you and your family?

$ ______________

S. Do you currently have a medical problem which requires on-going medical treatment?

1. Yes ____
2. No ____

T. Please put a check next to all illness(es) that you have had in the past two years:

1. Asthma ____
2. Ulcers ____
3. Pneumonia ____
4. Alcoholism ____
5. Colitis ____
6. Tuberculosis ____
7. Migraines ____
8. Hypertension ____
9. Arthritis ____
10. Weight problems ____
11. Sleep problems ____
12. Nerves ____
13. Diabetes ____
14. Specify others ______________

U. Have you had an illness or injury that has caused you to miss out on keeping a particular client?:

1. Yes ____
2. No ____

V. How important are improved medical benefits to you?

1. Very important ____
2. Somewhat important ____
3. Not important ____

W. Please add any comments you may have:

Thank you for your cooperation

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