Fragile Elders and Caregivers in the Milwaukee Community Options Program

Sharon M. Keigher, PhD
August 1999

School of Social Welfare
University of Wisconsin-Milwaukee
HANDLE WITH CARE

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This report is the second of two studies conducted by the Gray Market Study Project at the School of Social Welfare examining Milwaukee’s “gray market” in long-term, consumer-directed care. This project was funded with a $24,978 grant from the Faye McBeath Foundation of Milwaukee. The author thanks the foundation, as well as the many officials and agency personnel who helped us identify and reach respondents. Opinions expressed in this report are intended to be an accurate reflection of the respondents; the analyses and conclusions drawn are those of the author and in no way reflect the positions or policy of the Faye McBeath Foundation, the Milwaukee County Department on Aging, UWM, or any other agency.

The author gratefully acknowledges the contributions of Clare Luz, Sandra Prater, Ph.D., Lori Daugs, Kathy Bandstra, L’aina Rash, Jessica Dobeck, and Jessie Weathersby who conducted interviews and helped analyze these data.
This report examines services provided and received through the Community Options Program of the Milwaukee County Department on Aging during 1997. It is intended to give a “consumer perspective” regarding that program, including the views of the three key stakeholders in care: disabled older persons receiving services, their relatives, and the supportive home care workers paid by the county to provide personal care to these elderly clients.

The author and our researchers are deeply grateful to the 21 workers, 22 older persons, and 8 families who generously allowed us into their homes to see how important homecare really is and what their daily lives are really like. Without their honest and sincere cooperation with our interviewers, this study would not have been completed. Many of them stated frank hopes that their experiences could be useful in helping our community better understand their needs and improving care for others.

To protect their privacy and honor the confidentiality we promised them, we have changed the names and altered the identities of respondents throughout this report. Any mistakes of fact or implication, however, are the responsibility of the author alone, and should not be interpreted to reflect the views of the University of Wisconsin-Milwaukee, the Faye McBeath Foundation, the Milwaukee County Department on Aging, or any other agency.
Executive Summary

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Fragile Elders and Caregivers in the Milwaukee Community Options Program

This report is the second of two studies conducted by the Gray Market Research Project examining Milwaukee’s “gray market” in long-term, consumer-directed independent home care for older disabled people. This report examines services provided through the Community Options Program (COP) of the Milwaukee County Department on Aging (DOA). One of the oldest consumer-directed care programs in the U.S., COP allows service users to select their own supportive home care worker who is then paid directly by the county. This report presents a “consumer perspective” of COP by reporting how this program is perceived by the three “stakeholders” who have the greatest personal investment in the care it facilitates: the disabled older persons receiving services, their relatives, and the workers paid by the county who provide them personal care.

This project was funded with $24,978 from the Faye McBeath Foundation of Milwaukee; data were gathered in 1997. Opinions expressed in this report are those of the respondents who were interviewed: 21 workers, 21 elders, and 8 families. Using stories and vignettes to show their experiences and circumstances, we have tried to accurately reflect the sentiments respondents expressed to us. But to protect their privacy and confidentiality, we have changed the names and altered the identities of respondents throughout this report. The analyses and conclusions drawn, and any errors in fact, are the full responsibility of the author. This report does not reflect the positions or policy of the Faye McBeath Foundation, the Milwaukee County Department on Aging, UWM, or any other agency.

The purposes of this study were three. First, from older service users and their families, we wanted to learn what strategies are used to get the COP financial support, and how they find and manage personal care workers “on their own”. Second, regarding the workers who provide homecare to elders in the COP program, we wanted to study the conditions of work and how workers get hired, manage their work, handle interpersonal relationships, obtain payment, and comply with the program’s various administrative processes. Altogether we were interested in the social construction of independent homecare work, and how it differs from homecare performed by agency employees: what it is called, how tasks are defined, and whether there is consensus about these things. What are the strengths and limitations of a public policy of client choice in the selection of caregivers and supervision of workers on a day to day basis?

Part II of this report describes how we sampled the program users. Workers who were not related to their clients were contacted at DOA training sessions in January and February 1997. Confidential indepth interviews were conducted with the 21 selected workers, and followup interviews were held 4 to 6 months later. Interviews were also held with 17 of the 22 clients and 8 caregiver relatives.

Part III describes who and what we found after we had gathered together all our information on the 20 cases we studied. While substantially disabled (OARS scores averaged 16.9), some of these elders retain essential social roles in their families and neighborhoods, while others are relatively isolated in their homes. Most of these 21 elders live alone (21% have no children) while 7 live with children, and 4 live with their paid care workers.

Of the 21 workers, only 4 were currently married, 7 had minor children, and 17 had other family members relying on their income or personal care. The average hourly wage at first interview was $7.60 and at second interview was $8.00; half of the workers made $7.25 or less per hour at the first interview and of the 15 still doing COP work at 2nd interview, half were making $7.00 or less. Most (15 of the 21) had only one client at the first interview, and 13 worked for 21 hours or more per week for this client.

COP provides no retirement, sickness, or vacation pay and no health insurance, but 43% of the workers had health insurance through their husbands’ employment, Medicare, or other employment of their own. Four had no insurance at all, 3 had only the County Medical Indigent services, 5 were covered through means-tested public insurance (Medicaid, Healthy Start). In other words, 57% had no health coverage or no entitlement to health care coverage. Unfortunately, with an average age of 46, well over half of the workers had health conditions requiring regular medical attention or preventive care.
Section IV details how clients, with the help of family members when they are available, manage the responsibility of hiring, supervising, negotiating with and firing “their” workers. The length of time together in the sample ranged from 2 months to 12 years, with 7 elders having had the same worker for five years or more. Clients placed high priority on hiring persons who are known and trustworthy; 9 elders (including 8 of the 10 African Americans in the sample) hired workers who they already knew. Only one of the 11 white clients had known her worker previously. Since relatives may be hired, they sometimes take over provision of care, and subcontract with non-relative workers. This flexibility allowed 4 of the 6 daughters of women in this sample who were living with their mothers to alternate duties with a paid worker. Clients living farther from the central city, who are typically white, had more difficulty finding available workers.

The diversity of needs and expectations presented by program users raise questions regarding what, if any, standards should be expected of independent workers. Examination of reasons that care is terminated reveals that behavioral problems and attitudes of some clients present special difficulties.

Section V details issues important to workers, including factors that make this work challenging. As a group many of these 21 workers had difficult childhoods. Currently life in central city Milwaukee (where 12 of the workers live) presents challenges related to personal safety, reliance on limited public transportation, lack of education, and lack of job alternatives. Most workers had family responsibilities; 8 had other jobs or school in addition to caring for their client, and so had limited flexibility in their availability.

Many workers did not see their homecare work as a career or even a job, so much as work that was convenient and satisfying for them because they liked their client; only 4 had training beyond the 40 hours provided by DOA. But many were extremely resourceful, reliable, and capable of using the discretion the program allowed them. All worked entirely on their own, but 11 could call upon their own friends or relatives, or could rely on friends of the client to help out. In the 4 to 6 months between our two interviews with them, 2 workers resigned, having had difficulties with the client or his family, one worker died, and 2 delivered babies. In addition, 3 clients were hospitalized and one daughter took over the paid care from the worker. Many unforeseen events can precipitate termination of a case.

Section VI examines where geographically the clients and worker dyads live, revealing significant racial differences in the experiences of black and white clients and workers. It then summarizes findings in terms of the strengths and limits of this consumer-directed, independent worker model of care (page 47). If finally comments on balance on the strengths of this model except for the disadvantage to workers of the county’s not extending to them better job protections such as health insurance and retirement benefits, and the opportunity to organize for their own interests.

The author thanks the generous workers, older service users, and families who allowed us into their homes to see how important homecare is to their daily lives. In sharing their experiences they hoped to help our community better understand their needs to improve care for others. Thank you also to the Faye McBeath Foundation and the many agency officials who helped us identify and reach respondents.

For more information or comments, please call:

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Approach to Providing Homecare Workers
I. THE GROWING NATIONAL AGENDA
CONSUMER DIRECTED HOMECARE

Background to this study: This report is the second of two studies conducted by the Gray Market in Homecare Research Project at the UWM School of Social Welfare examining the provision of long-term, consumer-directed homecare to older disabled people in the Milwaukee community. The first study, Common Stakes in Homecare of the Elderly, was, like this one, a qualitative study of a small selective sample of homecare users. However, older disabled persons who were receiving care in that study were paying for it privately with their own money. In both studies elderly consumers and/or their families employ an independent, self-employed person who provides personal care and other domestic services in their home.

These studies are unique in that they closely examine the relationships among the three parties in privately contracted homecare arrangements, the older client, the worker, and the client's family members. Having learned a lot about the relations between independent workers and the clients they care for in the first study, we were eager to examine another kind of independent homecare that exists in Wisconsin but which is subsidized by state government. The Wisconsin Community Options Program (COP), which operates in all 72 counties of the state, allows clients to hire their own worker who receives her wages from the state through the county program.

B. The Importance of Direct Payment of Homecare Workers: Why the Milwaukee Community Options Program (COP) is a National Model.

The state of Wisconsin has one of the oldest consumer directed care programs in the U.S. Its Community Options Program (COP), which began in 1982, has been administered by Wisconsin's 72 counties for almost two decades. The program allows each county to design its own care system for five different target populations including persons who are: age 60 and over (who must comprise at least 55 percent of each county's COP clients), physically disabled, mentally/developmentally disabled, chronically mentally ill, and chronic substance abusers. Consumers are encouraged by a county case manager to “hire” the “caregiver of their choice.”

COP enjoys enormous local popularity and is recognized all over the state and nationally for being “consumer responsive.” County officials run the program locally, deciding whether to hire their own staff, contract out all personal care services to private agencies, or pay contingent workers directly for the hours they work. Counties control who gets service and whether clients/consumers may choose a relative, household member, or anybody else to provide care and receive payment. If the county contracts the whole program to a local private agency, for employing only full time or trained nurses, the client will have fewer choices than if each client is free to “hire” from among people they already know or choose to have.

In Milwaukee, Wisconsin's largest county, most workers are selected directly by service users. Users may hire relatives, friends, or neighbors if such persons are available—this is entirely up to the client and/or her family. Payment checks are written by a “fiduciary agent” (a local accounting firm) to the employee, and may be sent directly to the employee's home or to the client who delivers it to their worker. (In practice this is done both ways). The program is means-tested with medical expense-related income deductions or co-payments required of elderly individuals whose monthly incomes exceed $608 ($833 for a couple). Assets of over $50,000 and an annual income above about $10,000 will disqualify a single person from eligibility, consequently about 40 to 50 percent of disabled elders in Milwaukee are eligible for COP with some paying larger co-payment than others.

In 1996 when the Gray Market Research project began, Milwaukee County's state funded COP Program was providing in-home care and services to approximately 4,000 frail and disabled elders, with about 2,000 more elders on its waiting list. A county with 172,400 citizens aged 60 and over, Milwaukee probably had about 35,000 older persons (20%) needing assistance with at least one activity of daily living (ADL) using national prevalence estimates (Hooyman & Kiyak, 1993, p. 25). And it probably had over 7,000 (4%) severely disabled elders needing help with three or more ADLs. Persons whose incomes exceed the financial eligibility criteria for COP are assumed to be able to afford to purchase assistance with their own income or savings.

Our interest in this research was driven first by the fact that little has been published about the provision of independent paid homecare anywhere in the U.S. and even fewer have been closely studied, despite the fact that myriad examples of direct payment, or consumer-direction, exist in state programs for the elderly. Many states and counties, like Wisconsin and Milwaukee, however, contract directly with individual independent homecare workers (some including rela-
tives) rather than voluntary community care agencies. A study of direct payment provisions to homecare workers conducted in Maryland, Michigan and Texas (Doty, Kasper, & Litvak, 1996) identified several strengths of this approach for older service users, along with complex administrative oversight responsibilities and liabilities for states. Ted Benjamin of UCLA is currently conducting a major evaluation of California’s Independent Home Support Services program. This program, the largest independent provider program in the nation, serves over 100,000 aged and disabled consumers. Preliminary indications are that, along with being less costly to the state, this sharing of care management responsibility with consumers and workers generates many multi-faceted positive outcomes for clients, not the least of which is user satisfaction.

The term “consumer-directed care” was coined some 15 years ago by the World Institute on Disabilities. It was stimulated in the U.S. by President Clinton’s ill-fated Health Care Reform initiatives of 1993-94. Calling for the integration of acute and long-term care, his Task Force on Long-Term Care proposed a new system of state per-capita entitlement dollars for disabled persons of all ages. The legislation would have supported comprehensive state planning and infused new funding three times what was then provided for long term care from all sources. Requirements proposed for state plans would have given states the option to “cash out” care for designated populations (Stone & Keigher, 1994). These long term care provisions were among the most popular of all Clinton’s reform proposals, surviving even the defeat of the rest of the plan in Congress by autumn 1994.

Our interest in consumer-directed care was also driven by two important local policy developments that have potential to affect Wisconsin’s market in independent homecare. One is Wisconsin’s aggressive pursuit of welfare reform which had already pushed some 48,000 AFDC Recipients (over half) into the workforce between 1988 and the end of 1996 (Rector, 1997, p. 25). Milwaukee County was expecting to see another 15 to 25 percent of its welfare mothers—some 1800 a month (DeParle, 1997)—enter the workforce during 1997 (Rector, p. 23). By early 1999, Wisconsin leads the nation in the proportion of AFDC recipients who have been nudged off the welfare rolls, and apparently into the workforce. Our concern was the potential impact of large numbers of welfare recipients suddenly available for employment and possibly entering the homecare field, particularly the “easy entry” field of independent homecare. What, we wondered, would be this market’s potential to absorb large numbers of new workers? Is there potential for slippage in both wages and quality of care, if large numbers of untrained workers enter this market?

Our other concern was Wisconsin’s public debate during 1996 and 1997 leading to proposals to restructure its system for providing Long Term Support to the aged and disabled. These proposals, which Governor Thompson has since named his Family Care Initiative, addressed the qualifications required of workers and standards for care, and proposed to situate managed care organizations between the client and worker (Walters, 1997, p. 1). Should policy makers be concerned about quality of care in independent homecare? And if so, do intermediary structures assure that quality will be any better than independent care?

How much choice do consumers—elders and their families—have, and want, in the selection of caregivers? How many options and choices exist for workers doing independent home care work? We believed that a lot can be learned about consumers’ and workers’ own preferences by examination of this existing program.

C. Purpose of this Research: Understanding Stakeholders’ Preferences Regarding Control of Care Delivery

This study had three goals when it set out originally. First, for older service users and their families, we wanted to learn what strategies are used to get the COP financial support, and how they find and manage personal care workers. Second, regarding the workers who provide homecare to elders in the COP program, we wanted to study the conditions of work for people, how they get hired, manage their work, handle interpersonal relationships, obtain payment, and comply with the program’s various administrative processes. Altogether we were interested in the social construction of independent homecare work, and how it differs from homecare performed by agency employees: what is it called, how are tasks defined, and is there consensus about these things. What are the strengths and limitations of a public policy of client choice in the selection of caregivers and supervision of workers on a day to day basis?

By the time this study began in January 1997, we had already learned a good deal about private homecare provided in Milwaukee by independent workers who were self-employed and paid directly by their clients. That study focused largely on the centrality of the preferences of the three “stakeholders” in that care:
the client, the family caregivers, and the paid independent workers who had contracted together to assure the provision of needed care. In this study we would be thinking about a comparison of the preferences and practices of “stakeholders” whose funding comes from the county. Did the same preferences hold in a public program for which only low-income elders were eligible? (This actual comparison will be the subject of separate report.)

The data presented in this report were gathered to explore situations in which consumers (elders and family carers on their behalf) essentially direct their own care. Interview data were gathered in private interviews with participants who described and discussed existing two- and three-party arrangements. The data (transcripts of those discussions and other information gathered) were examined to identify participants’ subjective assessments of their choices in receiving and providing eldercare.

These respondents were all involved in independent care arrangements in which disabled elders and family members hire and supervise “their own workers”; there is no agency scheduling or direct supervision of care. Case managers from the DOA conduct an assessment and determine the number of hours of personal care needed to be provided to a client per week. The case manager and client, in consultation with the client’s relatives when they are involved, choose the worker(s). Often the worker chosen is someone who has already been providing care. DOA then contracts directly to pay this individual upon submission of a form detailing the hours worked which is signed by the client or her representative. Scheduling, hours, and duties are simply agreed to by both the elder, sometimes with a family member of the elder, and the worker.

The key findings of this exploratory study are in the form of descriptive statistics, situations, and respondent narratives gathered by our researchers. Highlighted are the issues and central themes from these discussions with the parties contracting for care—elders, workers, and elders’ family carers—and their implications for interpersonal power, familiarity, respect, and communication. Close examination of their situations and stories suggests the policy implications of the COP program’s consumer-driven approach to care for disabled low-income elders. In receiving a subsidy to purchase and largely manage their own care, these low-income elders’ experience is qualitatively different from that of patients receiving formal or professional care through home health agencies.

II. THE STUDY: RESEARCH DESIGN, DATA COLLECTION AND SAMPLE STUDIED

A. The Research Methodology and Study Design

This study is a qualitative investigation of cases drawn from independent consumer-directed care arrangements already in place in Milwaukee, Wisconsin, in which the Milwaukee County Department of Aging pays for care provided by independent workers chosen by the clients. Clients are low-income disabled elders who receive assistance and services from the county. All disabled service users studied were aged 60 or over who individually (and sometimes with help) hire, or select, their own paid, non-related personal care workers who provide regular housekeeping and/or personal care or other assistance. These elders, and sometimes family members on their behalf, provide the necessary day-to-day supervision, control or negotiate the scheduling of care, authorize payments, and basically manage the care themselves.

The sample studied includes 22 disabled elders (of whom 18 were interviewed) who receive financial support through the Milwaukee County Department of Aging Community Options Program (COP) which “buys” personal care from independent workers chosen by the consumers. A total of 21 county subsidized workers who work for these 22 disabled elders were interviewed, along with 8 family members who also provide or help manage their care.

Table 1 displays the clusters of stakeholders around each elderly service user on whom we have data: 8 triads (elder, family carer, and worker), and 10 dyad (elder and worker) combinations, and 4 lone workers (for whom neither client or family carer were interviewed). Interviews were completed with 18 clients, 21 workers, and 8 family caregivers. Workers were interviewed twice for a total of 42 interviews, and all interviews were transcribed for a total of 68 transcripts. Data on the 22 disabled elders in the study is occasionally incomplete, because interviewers were unable to interview four of the elders due to their illness, preference, or scheduling difficulties.

B. Sample selection

A pool of potential workers to be interviewed was recruited by making presentations at worker training sessions conducted by the Department of Aging in January and February 1997 at sites throughout Milwaukee County. Over 50 individuals were identified who were currently doing private personal care work and were not related to their client. Then a convenience sample was drawn giving priority to workers whose clients and
available relatives were willing to be interviewed. From this pool workers were interviewed until we had over 20 cases.

All interviews were conducted between January and June 1997. All workers were interviewed twice, four to six months apart, and were paid $15 for the first interview and $25 for the second. Clients were each interviewed only once. A family carer or relative of the client was contacted in each case when they were identified and lived locally; a total of 9 family members involved with 8 elders were interviewed separately from their relative. Clients and family members were not paid except in three cases where very poor respondents specifically requested payment.

Contact was made with the workers before contacting the clients and family members, and workers who had more than one client were asked to suggest the one to be interviewed. (Only 6 of these 21 workers had more than one client at the time of the first interview.) Most interviews were normally conducted by two researchers, but some involved only one. Interviews were conducted privately, except with a few elders where a worker or relative helped by interpreting communication. Interviews were guided by a set of open-ended, semi-structured questions addressing the subjective dimensions of the current care arrangement, how care came about, how the parties perceived each others' needs and preferences, what care involved, how well it worked, and background information to help explain the current arrangement. Interviews were very free ranging, guided largely by the respondent’s willingness to talk and many interviews with workers continued for over two hours.

Interviews with older persons took from 40 to 60 minutes and included administration of a needs assessment using the Duke University Older Americans Resources and Services (OARS) instrument to standardize assessment and analysis. This assessment was supplemented when necessary by further questions of the family member or the worker. Clients were scored from 1 to 6 on Economic, Social, Health, Mental Health, ADL, and Total resource dimensions with scores correlating positively with unmet need. Ratings were discussed among the researchers to assure reliability.

C. The Researchers

This project was conducted by a team of students and research associates at the UWM School of Social Welfare. These included four undergraduate and three

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<th>Number of Cases Studied including</th>
<th>No. of Cases</th>
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<td>Triads (client, family carer, worker)</td>
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<td>Clients unable to be interviewed</td>
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graduate students, and one Ph.D., under direction of the Project Investigator. Teams of two researchers conducted most of the interviews. All interviewers kept field notes, written (typed) observations, and information sheets on each telephone and personal contact, and interview. These detailed records, along with the interview transcripts, comprise the data that is analyzed below.

D. Method of Data Analysis.

All interviews were completely transcribed to allow thorough narrative analysis. From these transcripts, cover sheets, and OARS assessment, key items of fact were identified and entered onto a spreadsheet software program for tabulation and analysis. All narrative transcripts were reviewed to identify comments and themes with strong subjective, emotive content. These then were abstracted, coded and considered in terms of how they reflect the whole group and subgroups within it. Specific comments reflecting the respondent’s subjective assessments of their own individual situation, including the other parties to it, were examined in depth. This report presents the major themes identified within these data.

E. Limitations of the Sampling Method.

Even though the elderly consumers studied here select, direct, schedule, and supervise their own caregivers, this study is not necessarily generalizable to consumer-directed care in other settings. Nor are these COP clients necessarily representative of Milwaukee’s existing private-pay market in homecare. The clients studied here are very low income persons, for example, receiving care through a program that is means tested (only about a quarter of Milwaukee County elders are poor enough to qualify financially). Presumably such clients do not have the resources to hire care privately. Also, black elders, because they are more likely to be poor, are over-represented among users of the COP program. In Milwaukee County, 12% of persons over 65 are African-American, whereas 45 percent of this sample are African-American.

Also, by excluding kin from our worker sample, we excluded about half of the COP workers in Milwaukee County, since the Department of Aging (DOA) believes that at least half of the 1600 supportive homecare workers it pays are relatives of the elders they care for. Consequently, we must not generalize from the cases sampled here to cases where disabled elders are cared for by paid family members. In addition, although in most cases it is not extensive, DOA provides case management for these disabled elders, providing a reassessment every 3 to 6 months, a nursing assessment as needed, and detection of gross negligence. Private pay independent care arrangements rarely have any oversight except by family members; the DOA is rarely involved unless elder abuse is reported by neighbors or others. With this extra oversight in the COP program, we assume that the cases sampled here are at least as well off as, and maybe better off, than disabled elders receiving no case management and no paid care at all.

The following report describes first the demographic characteristics of all the sampled elders, workers and family caregivers, then critically examines the interdependencies of these elderly clients and workers. It identifies several aspects of these interdependencies in the relationships between the consumers and their workers. These highlight the living arrangements of the lower-income elders, showing how these affect not only the well-being of the paid workers, but also the care choices and even preferences felt by the disabled elders. The report concludes by examining the implications of these arrangements for the well-being of all disabled elders, their workers, and families, suggesting some possible limits of “consumer-direction” as public policy.

III. THE INTERVIEWEES:
A SAMPLE OF LOW-INCOME DISABLED ELDERS RECEIVING COP SERVICE FROM NON-RELATIVES

A. Low-Income Elders Receiving COP Homecare

The clients sampled range in age from 60 to 94, with an average age of 78.3 years (as shown on Table 2). They are predominantly female, but 27.3% are male. Over half (54.6%) are European-American, with 45.7% African-American, and none Hispanic. Only two (9%) were currently married, while nearly half (48%) were widowed, three (14%) were separated, one divorced, and one had never married.

Only 38% (8) of this sample were living alone, while 62% (13) were living with others. Of the latter group, only the married two were living with a spouse, while 8 were living with an adult child—7 with a daughter and one with a son—and 4 were living with a non-relative who, in all cases, was their paid worker. The 38 percent (8) who lived alone were equally likely to be in a rental apartment or their own home, but in this whole sample only 4 (19%) own their dwelling. This is a major indicator of their low-income status, since three-quarters of older Americans generally own their homes.
Although not extremely old (see Table 2), these clients’ needs are greatest, as measured by their scores on the OARS instrument (displayed on Table 3), for assistance with activities of daily living (ADL), then physical health, mental health, and economic support. In some cases they reflect a population which has experienced premature aging as a result of deprivation resulting from lifelong poverty and racial and gender discrimination (Wilkinson, 1997). In other cases they reflect individuals who, having become ill or impaired in mid-life, became poor as a result of inability to work and loss of a spouse. Finally, in a few cases, they simply reflect individuals who, having lived well into their late 80s or 90s, are not ill so much as in need of help with daily activities. The “needs” of this group partly reflect the economic and medical eligibility criteria of the Wisconsin COP pro-

### Table 2. Demographic Characteristics of Elders Receiving COP Homecare

<table>
<thead>
<tr>
<th></th>
<th>N=21</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age</td>
<td>78.3 years</td>
</tr>
<tr>
<td>Age range</td>
<td>60 to 94</td>
</tr>
<tr>
<td>Standard deviation</td>
<td>9.8 years</td>
</tr>
<tr>
<td>Percent male</td>
<td>6</td>
</tr>
<tr>
<td>Percent black</td>
<td>10</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>2</td>
</tr>
<tr>
<td>Widowed</td>
<td>10</td>
</tr>
<tr>
<td>Single</td>
<td>1</td>
</tr>
<tr>
<td>Separated</td>
<td>3</td>
</tr>
<tr>
<td>Divorced</td>
<td>1</td>
</tr>
<tr>
<td>Elders who have no children</td>
<td>7</td>
</tr>
<tr>
<td>Living arrangement</td>
<td></td>
</tr>
<tr>
<td>Alone</td>
<td>8</td>
</tr>
<tr>
<td>With others</td>
<td>13</td>
</tr>
<tr>
<td>with daughter</td>
<td>7</td>
</tr>
<tr>
<td>with son</td>
<td>1</td>
</tr>
<tr>
<td>with spouse &amp; others</td>
<td>1</td>
</tr>
<tr>
<td>with spouse only</td>
<td>1</td>
</tr>
<tr>
<td>with paid worker</td>
<td>4</td>
</tr>
<tr>
<td>Type of dwelling</td>
<td></td>
</tr>
<tr>
<td>Own house</td>
<td>4</td>
</tr>
<tr>
<td>Rented home or apt.</td>
<td>5</td>
</tr>
<tr>
<td>Subsidized apt.</td>
<td>7</td>
</tr>
<tr>
<td>Living in others’ home</td>
<td>3</td>
</tr>
<tr>
<td>Familiarity with the Worker</td>
<td></td>
</tr>
<tr>
<td>Client knew worker before</td>
<td>9</td>
</tr>
<tr>
<td>Number of months with this worker</td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>2 - 144</td>
</tr>
</tbody>
</table>
The needs of the elders receiving COP care are diverse, since they suffer from a wide cross-section of impairments. Their situations are often fragile and unstable, but sometimes remarkably stable over time. Their medical diagnoses include conditions with permanent functional impairments such as paralysis, immobility, amputations, developmental disabilities, and cardiac disabilities plus dementias. For many care provision had begun with a catastrophic health emergency such as a surgery, stroke, or hip fracture, but for others it was a slow accumulation of conditions entailing gradual losses of functional abilities, strength, or energy.

The amounts of paid care received ranged from 10 hours to 60 hours per week. While two individuals (9%) basically received companionship, most (57%) received light care, while 33% received total care including heavy lifting and complete personal care (see Table 3). All received at least ten hours of paid care per week, 3 received 10 to 14 hours, but the other 8 received 20 to 60 hours. Even with this much paid care, at least 9 clients still required additional unpaid care from persons with whom they co-reside. Between the care provided by their paid workers and unpaid family and friends, these 9 received care round the clock—168 hours per week.

Some consumers were found to be supplementing the hours and/or wages of their workers with their own money. Some of this was paid by employed family carers co-residing with the elder who relied upon one or more paid worker(s) while they worked. The COP program, which hires clients’ relatives, permits elders and caring families considerable flexibility to employ the worker they want, or to provide that care themselves with compensation for the number of hours that are authorized. Some family members were the provider of record, but actually hired others to provide all or part of the care. Such subcontractual arrangements are illustrated in several cases below.

Household Patterns, Incomes and Roles

Only 4 (19%) of the COP clients owned their homes, two of which were in need of repairs. Four others held joint ownership with an adult child. Nearly 60% (11 of 21) were living in subsidized apartments (7) or in the homes of others (4). Incomes ranged from $484 and $800 per month, the basic social assistance and social security monthly payment levels. While none used food stamps, a few received meals on wheels, and at least five accepted food regularly from friends or family. The two married people in the sample included a man 92 years old, living with his 90 year old wife, and a 66 year old woman who had been bedridden with Multiple Sclerosis for ten years living with her husband. In both cases the spouses also required care and emotional support, although the workers’ contract and payment does not include the spouse.

Several features of the living arrangements of these elderly clients illustrate the constraints under which low-income elders live. While allowing elders to maintain their dignity and independence, these constraints often present special challenges to paid and unpaid caregivers attempting to deliver adequate care.

Co-residence. Medicaid sets a limit on the amount of paid care that can be provided for disabled elders living in the community, and there are physical limits on the amount of care that can be delivered to an elder living alone. Federal Medicaid rules require the state to limit spending for homecare to the cost of alternative care in a nursing home. Consequently, many in this sample who required substantial amounts of care were co-residing in creative ways that facilitated their receiving adequate social and financial support. Unable to rely on spouses (because so few had spouses), many had arranged their own housing to facilitate receiving natural social support and physical assistance from persons they knew. These are the kind of decisions that adult children, when they were available, had often taken into their own hands.

Nearly half (10 of 21) of these elders were co-residing with either grown children (seven with daughters, one with a son) or, in four cases, with others. Between family members and paid workers these ten elders were essentially receiving care 24 hours per day, even though only one client had more than two workers and received more than 48 hours of paid care per week. Sometimes extraordinary arrangements involved both family caregivers and paid workers.

How four clients came to be living with their paid workers is especially interesting. One of these was a developmentally disabled woman living in an adult foster home. Another was a very frail 84 year old woman who had been “taken in” by her “ex-daughter-in-law” who felt the care “Gramma” was receiving in a nursing home was inadequate. In the latter case, several teen-age children helped out.

Ms. B’s situation, described below, illustrates what social scientists call “mutual aid,” a shared housing
Table 3. Homecare Received by COP Elders

<table>
<thead>
<tr>
<th>Marital status</th>
<th>Percentage of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>9%</td>
</tr>
<tr>
<td>Widowed</td>
<td>48%</td>
</tr>
<tr>
<td>Single</td>
<td>24%</td>
</tr>
<tr>
<td>Separated</td>
<td>14%</td>
</tr>
<tr>
<td>Divorced</td>
<td>5%</td>
</tr>
</tbody>
</table>

| Percent living alone | 38% |
| Percent living with relatives | 42% |
| Percent living with non-relatives | 19% |
| Percent receiving 24 hour care/day | 42% |

<table>
<thead>
<tr>
<th>Hours of paid care received per week</th>
<th>Percentage of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Range</td>
<td>10 to 60 hours</td>
</tr>
<tr>
<td>Receiving 10+ hrs of paid care/week</td>
<td>100%</td>
</tr>
<tr>
<td>Receiving 20+ hrs of paid care/week</td>
<td>85.70%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>OARS Scores</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Social support</td>
<td>1.93</td>
</tr>
<tr>
<td>Economic resources</td>
<td>3.35</td>
</tr>
<tr>
<td>Mental health</td>
<td>3.4</td>
</tr>
<tr>
<td>Physical health</td>
<td>4.15</td>
</tr>
<tr>
<td>Activities of daily living (ADL)</td>
<td>4.58</td>
</tr>
<tr>
<td>Total OARS Score</td>
<td>16.9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Care needed (worker assessment)</th>
<th>Percentage of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Companionship mainly</td>
<td>9%</td>
</tr>
<tr>
<td>Light care</td>
<td>57%</td>
</tr>
<tr>
<td>Total care</td>
<td>33%</td>
</tr>
</tbody>
</table>

**Companionship**: Monitoring, social interaction, meal preparation, outings, respite support for family caregivers.

**Light care**: Companionship + total care, no heavy lifting, not full time.

**Total care**: All ADL (toileting, diapering, grooming, personal care), instrumental ADL (laundry, cooking, shopping), companionship, dispensing medication, personal care, exercise.
norm often prevalent in low-income ethnic and immigrant neighborhoods. Naturally occurring shared-housing arrangements like this are common in low-income and immigrant neighborhoods (Hoch & Slayton, 1989), and Carol Stack (1974) has described their vital importance in African-American communities. Perhaps unfortunately, they are often considered unusual, and sometimes even suspect, in European-American communities.

**Mutual Aid**

Ms. B, now 68, became catastrophically disabled from a shotgun blast at her back 18 years ago. She was attending a party, and “the bullets were meant for someone else.” Fifty years old at the time, after her release from the hospital and rehab, Ms. B. continued living with her husband until he divorced her. A couple of other living arrangements did not work out.

Then, 12 years ago, a friend and drinking companion who had known Ms. B since childhood “took her in.” She recalls that the home care nurses originally taught her how to do things for her, since Ms. B is paralyzed from the waist down and has little range of motion in her arms. Carrie, now 39 years old, and her husband have since provided their friend a room in their home. Carrie provides personal care, helping Ms. B transfer in and out of bed, into the bathtub, and other mobility. She does all of her cooking, laundry, cleaning, and shopping. Carrie’s daughter who lives in the upstairs flat, and Carrie’s husband, help out sometimes. Carrie has received COP payment throughout this time and has no other employment. Her COP earnings net $346 per month ($494 gross), her only income, for providing up to 21 hours of care per week.

Ms. B spends most of her time in her room. She receives a Social Security and Supplemental Security Income check of $600 per month from which she pays rent and contributes to household expenses. Together with Carrie’s husband’s income of $800, their pooled household income is about $1746 per month for three adults.

Both women described patterns of heavy drinking in the past. Carrie has been an alcoholic for 26 years and was drinking heavily at the time Ms. B moved in. Ms. B quit drinking a few years ago and Carrie, who says she has quit several times, has been sober for the past year.

When their own family is not available, a disabled elderly client can become extremely dependent upon “their” worker. Eleven (55%) of the 21 clients sampled had no local relatives or only minimal telephone contact with relatives, usually with a distant sibling, an ex-spouse or estranged children. (If these clients had had relatives nearby, it is likely that one of them might have been the paid carer instead of non-kin.) Besides having few financial resources, only 9 percent (2) were currently married. Their being non-married (widowed, divorced, and never married) partly explains their lack of social support, lack of relatives, and even lack of income in some cases.

Since COP clients may hire any family member except a spouse to be the paid carer, the involvement of the six daughters in this sample (among the 8 relatives interviewed) is interesting. Only one of these 6 daughters was serving as a paid care provider (along with a non-relative who worked 35 hours per week) at the time of our first interview, but five had been paid caregivers in the past (only one was not). Currently each daughter had hired a worker, and the three with the strongest occupational prospects were continuing to work full time. The daughters, all over age 50, expressed concern about needing to keep regular employment because they needed health insurance and pension credits. The workers they hired were on average ten years younger than themselves and had no health insurance. In these cases, typically the daughters and workers still shared care.

B. The Independent Homecare Workers in COP

While in some ways this sample of COP workers is similar to other front line workers in nursing homes and home health care, some distinct features make these independent workers quite different as a group from other long-term care workers. As shown on Table 4, workers ranged in age from 21 to 75 with an average age of 46; 33% were under 40 and 19% were over 60. As expected, all but one were women; 71% (15) were African-American, and 29% were European-American. None identified themselves as being Hispanic.

Only 3 of the workers were married, but at least 2 were in long term partnerships with men, and 4 were widowed. However, 6 had never married, and 7 were divorced or separated. Essentially, 85% of these workers were “on their own” financially.
# FIGURE 1. CASES BY ELDERLY CLIENT, RELATIVE, & PCW COMBINATIONS

## TRIADS INTERVIEWED (n = 8)

<table>
<thead>
<tr>
<th>Client (race, age)</th>
<th>Relative</th>
<th>Workers (gender, race, age)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mrs. Alice Sweet W94</td>
<td>Eve, Dtr*</td>
<td>Meg W51</td>
</tr>
<tr>
<td>Mrs. Nabors B82</td>
<td>Dtr</td>
<td>Lataisha, B21</td>
</tr>
<tr>
<td>Mrs. Bono W66</td>
<td>Husband*</td>
<td>Paige, W61</td>
</tr>
<tr>
<td>[Mr. K W92]</td>
<td>Wife, grndson*</td>
<td>Valerie, W24</td>
</tr>
<tr>
<td>Ms. Sharp W82</td>
<td>Dtr</td>
<td>Grace, B48</td>
</tr>
<tr>
<td>Mrs. Dorothy Witt W79</td>
<td>Molly Witt, Dtr</td>
<td>Angeline, B48</td>
</tr>
<tr>
<td>Mrs. Workman, B86</td>
<td>Jane Workman, Dtr*</td>
<td>Denise Trumbull, B43</td>
</tr>
<tr>
<td>Mrs. Coates B78</td>
<td>Jena, Dtr*</td>
<td>Gloria, B45</td>
</tr>
</tbody>
</table>

## DYADS INTERVIEWED (n = 10)

| Ms. B, B68 | No local family | Carrie, B39* |
| Ms. B74 | No local family | Lilly, B63 |
| Mr. Willis, B77 | No local family | FB31 (*her m lives with clt) |
| Mr. Joe Junkin, B73 | No local family | Jewell, B72 |
| Robert, W69 | No local family | Kim, B47 |
| Ms. W60 | No local family | Mary Baker, B55* |
| Miss B83 | No local family | Tommy Jones, B28 |
| Ms. B90 | No local family | Tommy Jones, B28 |
| Mrs. W83 | No local family | Vanessa, B22 |
| Gramma, W84 | No local family | FW44* |

### 18 Elders, 17 interviewed

## ONLY WORKER INTERVIEWED (n = 3)

| [Mr. W60s] | *[? declined intvw] | FW40s |
| [Mrs. Bell, B76] | *[son, no intvw] | FW44 & Tawana, B36 (2) |
| [Mr. W60] | No local family | FB75 |

### 21 Elders

### 8 Relatives

### 21 PCWs

[4 not interviewed]

Names listed are all pseudonyms that appear in this report; other code indicates gender, race and age.

[] indicates we have no client interview: Mrs. Bell was hospitalized, wkrs felt the two other white male clients would not do it; and Mr. K W92 was sleeping so we interviewed his wife.

* This relative or worker lives with the client.

Mrs. Bell who was hospitalized and not interviewed; she is the only client with 2 workers.

The only male worker, Tommy Jones, had 2 clients in the study.
Workers’ residential arrangements are especially diverse. Five are living alone, including 2 in their own homes, 2 in rented apartments, and 1 in a subsidized apartment. The two who owned their homes also had some income from rental units within them.

Three were living only with a husband or partner, including one pregnant worker. Three lived with parents who helped support them: in addition to the young woman noted below, these included a young college student and a worker aged 29.

Six were living with and supporting minor children, including one worker with five children ranging in age from 5 to 24. The other five workers were each supporting from 1 to 4 minor children, including one caring for a nephew. The worker most strapped financially was 21 years old and pregnant with her fourth baby at the time of our first interview; she was sharing her apartment with her father and a cousin and receiving child care help from a variety of relatives and friends including her COP client. Because of the recent W-2 welfare reforms, she needed her COP job to keep her AFDC and Medicaid benefits. The other worker who was on AFDC was using her COP income and the training it provided to get herself off AFDC and into a regular health care job. She and her three young children were subletting a small apartment temporarily from a friend to save money for a downpayment for a lease on a small house with an option to buy. A third mother with two teenage children, of whom one was disabled, was also renting. These three who were raising children were, in fact, living in rental apartments or upstairs flats costing from $350 to $450 per month. Their incomes were especially low, their resources tight, and their housing unstable; if these women lost their COP job they were likely to be evicted.

Three other workers had adult children living with them who, in most cases, contributed to paying rent and household expenses.

All in all, only 7 workers lived in homes they owned. These included the one that was an adult foster home, one who lived alone, two whose husbands were retired (one living with a daughter), one whose grown son lived with her, and two other parents: the one who was raising her nephew and the one who had five children.

Qualifications for the Work

About a third of workers mentioned or otherwise revealed that they had reading or other learning difficulties. Thirty-eight percent (8) had not completed high school while 43 percent (9) had completed at least some college credits, including two who had Bachelor’s degrees, one in sociology and one in dental hygiene. Only 5 workers had had any training at all for personal care work beyond the 2 week course required by the Department of Aging beginning in 1997. Several of these workers appear to have been impeded from becoming credentialed or certified as health care professionals because of educational deficits and learning difficulties (see Table 5).

This bimodal distribution, or split labor market, greatly disadvantages workers at the bottom. For example, among workers with the least education and
Most other disadvantages, several had significant problems in presenting themselves to potential employers or others and making a “professional.” Several had missing teeth and/or ill-fitting dentures. Besides compromising their appearance, dental problems often made the worker’s speech difficult to understand. Others had speech impediments, spoke with heavy dialects, used unusual grammatical constructions, or frequently used colloquial expressions that compromised the listener’s understanding. Some had visible health problems, such as obesity or chronic pain which made them fatigue easily, unable to stand for long periods, and obviously vulnerable to work injury (detailed further in section VI.B below). Altogether these appearance, speech, and health disadvantages were reasons women might be shy, uncomfortable around strangers, non-assertive and lacking in confidence, or apprehensive about undertaking heavy care duties. This raises questions about the disadvantaged workers’ primary reasons for doing homecare work, and especially for being self-employed. For them, independent care work may be more of a trap than an opportunity. (This is explored further in section V.C. Compensation below.)

Finally, many workers had potential difficulty obtaining regular reliable transportation to work. Thirty-eight percent (8) lived close enough (within a mile) to walk to their current client’s home, but only 57% had a car available to drive to work. If living too far from, or unable to walk, to their clients’ homes, workers without cars relied upon the public transit system or rides from friends. However, bus routes were much less frequent, if present at all, outside of the central city in higher-income neighborhoods where white clients, who were widely dispersed, were more likely to live. These difficulties are detailed in section V.C. below.

Workers’ Earnings from COP and Other Independent Care Work
At the first interview the average hourly wage from COP for these 21 workers was $7.60 and by the second interview the average had improved to $8.00. By the second interview, however, only 15 workers were still doing homecare work (see Table 6) and, unfortunately, wages did not improve for all in this 4 to 6 month period. Half of the workers were making $7.25 or less per hour at the first interview (median wage), and half of the workers still in COP were making $7.00 or less per hour by the second interview.

Since workers’ actual earnings from self-employment depend on the number of hours worked per week times the hourly wage, plus other sources of household income, working more hours yields a distinct improvement in income for most workers. The real explanation for their income improvements is that workers who were continuing with homecare work at the second interview had taken on more clients.

At our first interview, only one worker was working on COP less than ten hours per week; 62% (13) of the workers were working 20 hours or more and over 71% had only one client—the individual who had chosen them to be their caregiver. Only 28% (6) had two or more clients. By the second interview, however, the proportion with 2 or more clients had increased to 46%. Possibly workers who stay with this work improve their skills at making contacts and obtaining referrals.

These self-employed workers tend to rely on a combination of income sources which sometimes are in constant flux. For example, at the time of our first interview, while only 6 workers had a second client (or more) in addition to the primary client we interviewed, 8 workers had other jobs. Three did related care work for a day care center, a group home, and a private home health care agency. Four others worked part-time at clerical work, teaching and catering, clerking

<table>
<thead>
<tr>
<th>Table 5.</th>
<th>Workers’ Human Capital</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>N (21)</strong></td>
<td><strong>Percentage</strong></td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>8</td>
</tr>
<tr>
<td>High school graduate</td>
<td>4</td>
</tr>
<tr>
<td>Some college</td>
<td>7</td>
</tr>
<tr>
<td>Assoc. or prof. degree</td>
<td>2</td>
</tr>
<tr>
<td><strong>Training for Personal Care Work</strong></td>
<td></td>
</tr>
<tr>
<td>On the Job</td>
<td>21</td>
</tr>
<tr>
<td>Hospital/Nursing Home Program</td>
<td>1</td>
</tr>
<tr>
<td>CNA Program Only</td>
<td>2</td>
</tr>
<tr>
<td>LPN/RN</td>
<td>0</td>
</tr>
<tr>
<td>Personal Care Trng (Intfth or FamS)</td>
<td>2</td>
</tr>
<tr>
<td>Required DOA PCW Trng</td>
<td>21</td>
</tr>
<tr>
<td><strong>Transportation Available</strong></td>
<td></td>
</tr>
<tr>
<td>Have a car</td>
<td>12</td>
</tr>
<tr>
<td>No car</td>
<td>7</td>
</tr>
<tr>
<td>Get rides occasionally</td>
<td>2</td>
</tr>
<tr>
<td>Rely on public buses</td>
<td>9</td>
</tr>
</tbody>
</table>
Household income depended on the income sources that the worker and other household members could piece together. Workers with fewer COP hours usually had income from other employment, pensions or public assistance, or partners and others, such as teenage and young adult children who contributed to household maintenance. Some also had small amounts of rental income, typically from renting a duplex unit. Indeed, counting all possible income sources, only two workers lived entirely on the income from their COP client; these wages were in the amounts of $1212 and $954.

At the first interview, workers' total household incomes were estimated to range from $450 to $5,800—the wide dispersion accounted for largely by 5 households with incomes of over $3,000 per month. These included 3 husbands with salaries from $2500-3400, the worker employed at the utility company, and one worker living with her parents who both worked. On the other hand, the partners of two workers had incomes of from $200 to $800 per month, one being an artist whose income depends on sales. Another worker's only other income was that of a child living with her (earned or SSI?). Workers' own total earnings ranged from $450 to $2864 per month, including the COP income. Clearly, their husbands'/partners' incomes were even more disparate than those of the homecare workers.

Table 6. COP Workers' Wages, Caseloads, and Hours at 1st and 2nd Interviews

<table>
<thead>
<tr>
<th>Hourly Wages</th>
<th>1st Intvw</th>
<th>2nd Intvw</th>
</tr>
</thead>
<tbody>
<tr>
<td>n=21</td>
<td>n=15</td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>$5 to $12</td>
<td>$5 to $11</td>
</tr>
<tr>
<td>Mean wage per hour</td>
<td>7.60</td>
<td>8.00</td>
</tr>
<tr>
<td>Standard deviation</td>
<td>1.18</td>
<td>1.13</td>
</tr>
<tr>
<td>Median wage</td>
<td>7.25</td>
<td>7.00</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of Independent Homecare Clients (Caseload) per Week</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 clients</td>
</tr>
<tr>
<td>1 client</td>
</tr>
<tr>
<td>2 clients</td>
</tr>
<tr>
<td>3 clients</td>
</tr>
<tr>
<td>4+ clients</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Hours of Independent Homecare Work per Week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Range of hours worked per week</td>
</tr>
<tr>
<td>0</td>
</tr>
<tr>
<td>&gt;10 hours</td>
</tr>
<tr>
<td>11 to 20</td>
</tr>
<tr>
<td>21 to 35</td>
</tr>
<tr>
<td>&lt; 36</td>
</tr>
</tbody>
</table>
Finally, the county deducts Social Security contributions (7.2% from the worker’s wage, and another 7.2% in the county’s own funds), and federal and state income taxes from COP wages. It also makes Workers’ Compensation (the county is self-insured) and Unemployment Compensation contributions, although only full time workers typically collect Unemployment Compensation. However, the county makes no health insurance coverage or buy-in provision for COP workers.

Workers health problems. With a mean age of 46, most workers had health problems of some types. Examples of health problems mentioned to our researchers by 13 workers at their first interview included:

1. Crohn’s disease, asthma, knee problems, arthritis, recent skull fracture
2. Alcoholism
3. Heart condition, hypertension, thyroid disease
4. Cancer
5. Lupus arthematosis
6. Knee problems
7. Hypertension, arthritic knees, asthma, hernia surgery, back paid, obesity
8. Cardiac surgery last year, now much better
9. Narcolepsy, possible brain tumor
10. Hypertension, diabetes
11. Recent gallstone surgery, chronic sinusitis

In addition, two workers were pregnant (both were covered by Medicaid Healthy Start which paid for their deliveries).

The nature of these conditions indicate that over half of the workers were in need of at least regular medical monitoring, and several needed ongoing treatment. One in five (22%) of the workers had no consistent source of health care (see Table 5).

Lack of Health Insurance Coverage. Only 43% (9) had their own health insurance coverage (see Table 5). All 4 of the married workers had health insurance through their husbands’ employment, one through other employment of her own, 2 through Medicare coverage with their own supplemental insurance policies, and 2 had private insurance they paid for out-of-pocket. Fully 57% (12), however, had either no health insurance at all (4) or depended on means-tested Medicaid (5) or the county G.A. Medical Indigent program (GAMP) (3). These included the two pregnant workers who both delivered their babies through the Medicaid Healthy Start program.
Medical Bills. Several workers suffered particular anxiety over unexpected and high medical bills that had placed them under excessive financial strain. The worker who suffered from narcolepsy was suspected of having a possible brain tumor, and his doctor had ordered a CAT scan that cost $2,000. He was now paying a little every month toward this bill out of his monthly income of $500, although he was no more certain of the cause of the problem than before. Gloria’s daughter had suffered a complex fracture of her arm and hand in a fall two years ago, for which Gloria was still paying on a bill of $2200 to Children’s Hospital. She was grateful for the $600 that had already been paid by government and the hospital’s charity care fund. Denise was also deeply worried about bills of $1000 she’d incurred from two Emergency Room visits because of falls in the previous winter.

The County General Assistance Medical Program (GAMP). Three workers (numbers 1, 5, and 10 on the list of medical problems above) mentioned being covered by GAMP, the county General Assistance Medical Program for indigent people. As can be seen, all three have chronic health conditions requiring close monitoring and periodic treatment during acute episodes. Only one has a regular source of care, and that is through one of the county funded Rainbow Community Clinics. While one of these women was providing care to her particular client because she was his friend, the other two were really committed and working to make homecare their “second career.” Unfortunately, this will be difficult; as they recruit more clients and more hours, making more money, they will become disqualified for GAMP health care benefits (that they cannot live without) when their incomes exceed the limit.

The GAMP Health “Insurance” Catch 22

One of these workers hopes to start her own case management business. She had learned through a sympathetic eligibility specialist that the income limit for GAMP was “under $800 per month.” She was frustrated that county officials had not told her of this income limit before, as she had previously filed for bankruptcy due to medical bills she incurred from a skull fracture she got in a fall on some ice. With this new information, she may now be aiming to keep her “legitimate” earnings below that $800 ceiling. By our second interview she had quit her 20 hours a week job with an agency and taken on two new private-pay clients (non-COP); private pay income will be easier “to hide.” She faces a Catch-22, unlikely to either qualify for or afford health insurance at all with her now documented pre-existing conditions. She is making rational decisions, but ones she could easily be made to feel ashamed about.

Another worker, who had known about the GAMP income limits for years, revealed some of the ways that she had devised to “keep her income down.” Actually maintaining three different jobs, including her own business (a school), but by taking much of her earnings through bartering, only her COP income and some of her catering income is “on the record.” For one job she is “paid” in food and board for a large pet, and as a teacher she is paid out of the (minimal) profits of her business. She volunteers at a food pantry, which allows her to get what she needs and she owns her home which further allows her to keep her expenses down. This worker, who is in her 50s, is skillfully managing her access to the free county health care system out of necessity. Having been chronically ill for many years, she knows from painful experience that receiving regular health care is a matter of life and death for her. Work for COP allows her to schedule and work at her own pace, further helping her accommodate her illness. In fact, however, she only did this because the client was a friend, and when this client passed away she would not take another.

Interestingly, both of these two workers had college degrees. Unfortunately, some workers with similar needs were not so well informed; few were aware of the GAMP program at all.

In sum, while at first glance hourly compensation for these independent COP workers appears to be adequate, “access” to clients paying higher hourly wages was worst for the very workers whose families needed income the most. These were the workers who tended to lack transportation, training, experience, personal relationships and linkages to clients through social institutions. Many workers also preferred to, or had to, work near home because of their own children and other family obligations. Others worked near home because they had no car, and still others, simply because their only client had been a nearby friend or neighbor before becoming disabled and needing care.
C. Relatives and Family Caregivers of COP Clients

As noted above, a large proportion of the elderly clients in this sample had no relatives at all who could be interviewed. Only 8 family members were formally interviewed, including six daughters and 2 spouses, although researchers did meet and talk informally with other relatives who provided some useful information. Our key impressions regarding family caregivers is their deep commitment to their relatives' wellbeing and the essential ways they help elders make decisions about care when they are available. Family members are included in the “consumers’ perspective” below on the processes and issues that arise for elders receiving services through the COP program.

Table 7. COP Workers’ Sources of Health Insurance Coverage

<table>
<thead>
<tr>
<th>Have own insurance coverage</th>
<th>No.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Through spouse’s/parents’ employment</td>
<td>4</td>
<td>19%</td>
</tr>
<tr>
<td>Private insurance (out of pocket)</td>
<td>2</td>
<td>10%</td>
</tr>
<tr>
<td>COBRA (out of pocket)</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Through other employment</td>
<td>1</td>
<td>5%</td>
</tr>
<tr>
<td>Medicare and private supplemental</td>
<td>1</td>
<td>5%</td>
</tr>
<tr>
<td>Medicare and private supplemental/own retirement benefits</td>
<td>1</td>
<td>5%</td>
</tr>
<tr>
<td>Independent personal care work</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Total with own health insurance</td>
<td>9</td>
<td>43%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Have public means-tested insurance or no coverage</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Veterans Administration</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Medicare and Medicaid</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Medicaid and/or Health Start</td>
<td>5</td>
<td>24%</td>
</tr>
<tr>
<td>County GA Medical Program</td>
<td>3</td>
<td>14%</td>
</tr>
<tr>
<td>Have no health insurance of any kind</td>
<td>4</td>
<td>19%</td>
</tr>
<tr>
<td>Total with public or no health insurance</td>
<td>12</td>
<td>57%</td>
</tr>
<tr>
<td>Total</td>
<td>21</td>
<td>100%</td>
</tr>
</tbody>
</table>

IV. THE PROCESSES OF COP HOMECARE FROM THE CONSUMERS’ PERSPECTIVE

The following vignettes and descriptive detail are presented to illustrate some of the most important aspects of independent care as it is experienced by elderly disabled individuals using it. They summarize situations that we observed and that were described to us. Every effort has been made to keep the stories “true” to the sentiments expressed by the respondents by quoting directly from their statements. However, pseudonyms are used and sometimes identifying features have been changed to protect the identity of specific individuals and families.

A. Finding and Choosing A Worker:

1. The Pre-existing Familiarity of Many Black COP Clients with Their Workers

At least 9 of the 21 COP clients in this study already knew their worker before “hiring” them, and 8 of these 9 clients were African-American. Indeed, half of the 16 black elders in this sample had known their worker before “hiring” them, many since childhood. Several workers were friends or the children of friends of the client, reflecting the many inter-family friendships among African-Americans in Milwaukee that had originated with previous generations in Mississippi, Arkansas and other southern states.

One remarkable young man, for example, had been providing care to several elders in his neighborhood long before the COP payment was arranged. Like
four other workers in the sample, his parents, with whom he lived, had strong lifelong ties with these neighbors through their church and other civic activities. "His ladies," remembering his birth, talked at length about what a blessing he was to his mama and others that knew him.

Other workers "just happened to be around" when their disabled friend needed help. Becoming a regular provider was "no trouble" for them, and provision of "natural help" was an expected part of the reciprocal relationships they regularly engaged in with other individuals and families. Mr. Willis, for example, had been friends with his worker’s mother; when he faced being placed in a nursing home 7 years ago, he asked if she would move into his apartment and care for him. Since then, in return, he has given her free rent in his subsidized apartment where she sleeps on a convertible sofa. It is less clear how Ms. B, described above in "Mutual Aid" (p. 12), came to live with her young friend Carrie, but Carrie has simply considered Ms. B a normal part of her household ever since.

A few clients knew their worker through the close-knit familiarity of their neighborhood. One worker, living in a subsidized senior apartment building, had noticed that one of her disabled neighbors was not being cared for adequately by her COP worker. She looked unkempt and unsafe out shopping by herself. After getting to know the client, because she was worried about her, she learned that the client had a case manager. She then looked up the case manager and suggested that the other worker be replaced by herself.

Another worker, Kim, had come to know Robert, a formerly homeless alcoholic, because they had worked together delivering newspapers. Not especially close friends, Kim didn’t really know much about Robert’s background, but she happened to be visiting his building one day when Robert passed out in the lobby. Kim instinctively offered to help and then became his COP worker, although she has no interest in taking on other elderly clients or making this a career. Robert, age 69, is a very sociable man and manages several friendships among his elderly neighbors.

Some older people had been on the COP waiting list for eligibility for many months. Most had begun receiving assistance during that time by either paying out of pocket or relying on friends or family. They naturally turned to these same persons to continue when they became eligible for COP. Many white families, on the other hand, had no idea where to look when they needed a worker. Compared with the black clients, the white clients were much less likely to ask friends, or even to know women who were already doing homecare work. They were more likely to have found workers through newspaper ads or professional referrals, through hospitals and agencies, or through persons who knew others through their own employment. Some black families recruited workers this way as well, and in cases where no family was available, some clients had also relied on the DOA case managers, but this was a distinct minority.

Clients who did not know their workers previously found them through a variety of means. Of the seven black workers who had not known their clients before, three had found them through a DOA case manager. The other four had found them through: a friend at her other job at a group home, a pastor, a cousin who already had the job and was leaving, and a newspaper ad. The five white workers had met their clients through: jobs at a day care center and a home health agency, a husband’s work colleague, a DOA case manager, and answering a newspaper ad.

2. Family Management and Control

COP provides discretion to the elderly client, as well as to persons already invested in caring for her. In cases where family members are present, especially when they co-reside with the client, they are welcome to assume as much responsibility as they want and can. When it comes to stretching funding, it appears that Milwaukee County’s case managers trust families, as well as elders, who are determined to avoid a nursing home placement to figure out the most functional and cost-effective ways to do this. An example is a family we learned about through two workers who cared for the same client, although we never met either the family members or the client.

Family Management of Mrs. Bell

Mrs. Bell, a 76-year-old black widow has required care 24 hours per day since a devastating stroke four years ago left her bedridden. Continuing to live in her home with one of her grown sons, Mrs. Bell receives care throughout the week from 6 different paid workers plus family members. Paralyzed and unable to speak, she needs to be continuously monitored, fed through a G-tube, helped to drink fluids, changed, and bathed. Her body must be turned and repositioned every two hours, including during the night. A very religious family, one of her sons manages the COP pay-
3. Helping Others By Helping Oneself.

Discussion revealed, for example, that while families have norms about who will be the primary caregiver for an elderly relative, low-income families also have norms about which family members should “get the work” created by receiving the COP payment. We could see this especially in the experiences of three workers who, because of pressure from the AFDC welfare reforms in Milwaukee in 1997, needed to find work and get off welfare. Mrs. Nabors’ situation is typical of the way that friends and relatives are relied upon to helped out.

**Mrs. Nabors’ Complex Social Roles**

Mrs. Nabors’ family and her caregiver’s family, both African-American, are long term friends. Decades ago they moved to Milwaukee together from Mississippi and they have always lived within walking distance of each other. At 82 years of age, Mrs. Nabors is now the matriarch of both families; she remains a vital mainstay of support for members of both families despite her arthritis, glaucoma, asthma and chronic bronchitis.

In the context of W-2, Mrs. Nabor’s daughter, who had been her paid caregiver, had “given up the job” so that their friend’s daughter, Latasha, a 21-year-old mother with four small children, could have it. By working and earning $600 a month through COP, Latasha was able to keep an AFDC benefit of $190 per month and maintain her children’s Medicaid coverage. In addition, the job “provides” child care because she brings her children with her to her client’s familiar home. Indeed, Mrs. Nabors sometimes tends the children herself. COP has become a vital source of income shared by Mrs. Nabors’ friends and family. Even though she now needs assistance with shopping, cleaning, cooking and bathing, Mrs. Nabors’ wise counsel is sought out. As in the 1997 film, *Soul Food*, “Big Mama’s” role as the central decision maker in this primary group is still essential to this whole family group’s survival.

With payment available for the work done for them through COP, elders sometimes are literally empowered as contributing community members. Many of them naturally feel a concern for their workers’ wellbeing as strongly as their concern for themselves.
4. Family Freedom NOT to be the Primary Caregiver

Close analysis of the six cases in which disabled women were living with their daughters reveal COP’s fundamental flexibility in honoring family caregivers’ choice to either become the paid caregiver, or maintain their own employment (see Keigher, Bandstra & Prater, 1999, for a more complete analysis).

At the time of our first interviews, five of these six elderly women in this sample (Sweet, Witt, Workman, and Coates and Nabors), were co-residing with their daughters. The sixth, Mrs. Sharp, had always been living independently in her own apartment, although her daughter had previously been the paid worker and was still coordinating her mother’s care. Two daughters, Sweet and Willard, were working full-time outside of the home in addition to caring for their mothers without compensation, each with a paid personal care worker coming five to six days a week. Ms. Willard was caring for her brother and a foster son, in addition to her mother.

Daughters Witt and Peyton were both working part-time, with Ms. Witt also responsible for her learning disabled sister, while apparently neither Mrs. Sharp nor Mrs. Nabors’ daughters had any outside employment. Each client had a regular personal care worker paid by COP at the time of our first interviews, but it turns out that five of these six daughters had received or would receive payment through COP.

These daughters’ choices to be, or not to be, the primary paid worker, is especially interesting as is how the daughter and paid worker divided, or shared their responsibilities and the payment, and how the hours of care provided through this direct payment alleviated family caregiver burnout. The flexibility allowed to family caregivers, along with the unusual degree of discretion allowed to both clients and the workers regarding how personal care is delivered, is COP’s most profound strength.

This strength is illustrated in the case of Eve Sweet, a 57-year-old hospital librarian who brought her then 90-year-old mother from another city to live with her four years ago. Eve has been able to maintain her career because of COP, while still giving all she can to her mother.

Blending a Career and Family Caregiving As Alice’s only daughter, Eve had little real choice about becoming her mother’s caregiver. She had begun helping long distance in 1985, moving Alice first to an assisted living center which, as Alice became increasingly confused, was eventually unable to prevent her from wandering away. Four years ago Eve moved her mother into her own small apartment. Later, with an unexpected inheritance, Eve was able to buy a home for the two of them. One of Eve’s brothers moved back to Wisconsin to be near his mother and sister, but he rarely visits, and another brother’s child moved in to help, but this didn’t work out. In emergencies Eve has relied on neighbors and a retired nurse friend to provide care, and once when she was hospitalized herself, a neighbor moved in for a few days to care for Alice full-time. Eve’s having “fallen into it” is similar to the situation of many adult daughters.

While on the waiting list for COP until one year ago Eve used her own and her mother’s incomes to pay for day care. Having worked for 18 years at the hospital, Eve earns about $25,000 per year after taxes. Alice’s Social Security and a small pension adds about $1,050 per month; she is not Medicaid eligible. When pooling their resources, their monthly household income is less than $3,000. COP eligibility immediately relieved the monetary stress, funding Alice’s care and creating more independence for both of them. When we met them, DOA was paying for day care for Alice from 9:00 to 4:30 daily and had covered some home modifications, including an outside ramp and bathroom guardrails.

Eve got her mother into the daycare center immediately, but with her work schedule, getting her mother up and ready to go, and picking her up in the evening was difficult until Eve found Meg who was working at Alice’s daycare. Now Meg drives Alice home from the center at 4:30 p.m. and stays with her until after 6:00 pm, sometimes starting dinner by the time Eve returns from work. Eve then is alone with her mother in the evening and all night; her sleep is interrupted every night as she gets up to toilet her mother. “There are nights when I literally do not sleep,” remarks Eve, the edge in her voice revealing her fatigue. She is committed to doing what is right, fulfilling an obligation her mother filled for her mother, even though she knows it is taking a toll on her own health.
Meg comes again, letting herself in at 6:00 the next morning, helping Alice wake up slowly, and allowing Eve time to get dressed without interruption and leave for work on time. Meg remains with Alice, bathing and dressing her, feeding her breakfast, and transporting her to day care by 8:30.

COP also allows a few respite hours with which Eve pays Meg to “sit” so she can do errands and laundry on Saturdays. Relaxation is important to Eve who has her own health problems; she has had eye surgery, and has back pain and a bad knee. With her mother’s care covered, she has spent her vacations working at a friend’s horticulture business, “because it relaxes me.” Eve repeatedly states how important it is to have someone with whom she shares this job, that Meg is a “godsend” coming so early in the morning, and a double bonus working also at the day care center.

Note, however, it is fundamentally the worker’s flexibility, wrapped around the needs of the caregiving household, that puts up the gaps in care and facilitates the higher level employment of the family caregiver. And Meg is a “rare bird.” Now in her second career after 30 years as a sales representative, she has a car, has grown children, lives alone, loves doing this work, and hopes to develop her own care management business. She has flexibility, enjoys accommodating others, and is really good at solving domestic dilemmas. She and Eve both have careers because of COP.

In only one other case, Ms. Workman, did we find this much care being provided while facilitating a family member’s keeping a professional position. In the other four cases where a daughter was co-residing with the client, the daughter had chosen at different times to be the paid provider.

Unfortunately, the one stress that is not relieved by the PCW for any daughters in this sample was the personal care their mothers required during the night. Four of the 6 daughters reported that, like Eve above, their sleep was interrupted nearly every night to assist their mother in getting to the toilet. This urgent need is what led at least two of the daughters to give up their day jobs altogether.

B. Client Choice and the Critical Importance of Trustworthy Relationships

Eve also emphasizes the importance of her trust in Meg. Working together but rarely seeing each other, she and Meg respectfully do many small considerate things for each other, back and forth. Such respect and reciprocity is essential for the elderly client to feel safe. Indeed, it is the poorest clients who own the very least who stand to lose the most if an untrustworthy or unreliable worker enters their personal space. The poorest elders in this sample talked freely of the risks of living in neighborhoods with high rates of theft and interpersonal violence. Joe Junkin, for example, a very large, outspoken 73-year-old black man, was frustrated and angry that people had stolen money and clothes from him, and even his telephone. “I just don’t like them thieves. Ya know why? Because I used to be a thief myself!” He carries a knife and sometimes “a piece.” Yet, he speaks quietly and with respect of his two current workers.

And it is mutual respect and trust that allows elders and workers to depend upon each other. Indeed, many elders’ and workers’ language is laced with strong words about trust, their descriptions of workers’ trustworthiness some of their most potent language.

There is a special dynamic to how elders and families learn to trust an outsider entering their home and private domain. Experience builds, gathering momentum, as opportunities to prove themselves build incrementally on both sides. After 8 months with Angelina, Molly Witt says “I trust that woman. She does things I don’t even ask her to do.”

Given the COP philosophy, competent elders are aware that they are responsible to effectively employ their helpers. Mr. Junkin’s case manager told him, “I’m the boss. They have to do what I tell them. She told me ‘You’re the boss. I’m over there (at the office). I can’t do that.’” So does he set the workers’ schedules and supervise them? “No, anytime they show up. We don’t set hours.” But he could be very specific about what the workers are to do. “If a room needs cleaning (or the stove, or the bathroom), it gets cleaned.” (And, we noticed, the rooms were clean.)

Through this process of interpersonal trust building and employment by families, some workers are “given a chance” who might otherwise be considered unemployable in the health care industry. The state’s certification requirements for being a nursing assistant, and the qualifications expected of staff at nursing homes and home health agencies make it very difficult for some individuals to be hired. Agencies run a risk hiring persons with a police record, or without a high school diploma, but families who are able to monitor workers closely feel that such individuals can and do perform very well.
The case of Mrs. Bell, described above, is an example of the kind of family monitoring of PCWs that protects clients, and at the same time allows opportunities to workers who might otherwise be considered marginal or even unemployable. One of Mrs. Bell's workers admitted to us she had a criminal record, a drug related felony. And we wondered about the worker chosen by Jane Workman who had turned out to be quite effective.

**Growing Trust, Growing Possibilities**

Jane Workman hired Denise Trumbull, age 43, just as her mother Ruth moved into her home and became eligible for COP. Ruth, who at 86 had had a stroke, was confused and unable to walk, and needed constant assistance with nearly everything.

Jane is an official with a public employment agency and works a 40+ hour week. Denise was living two doors away from Jane with her mother, who is Jane's friend. Born into a large family in Mississippi to a nurse and a steelworker who later moved the family to Chicago, Denise grew up quickly caring for her younger brothers and sisters. She had a baby at age 13, and raised three children who are now adults in Chicago.

Denise's job history is sketchy and she speaks with an air of bravado. She says she has done personal care work for over ten years, most of it in Illinois where she had eight clients. She likes personal care work, "That's just in me, I want to be able to help," she says. But she is evasive about her background and appears to have unrealistic aspirations, stating that she plans to become a surgeon. Admitting she has been fired from it before, she
feels the home care work she does is equivalent to working in a hospital.

One wonders if Denise has used drugs, been in jail, or has some emotional instability. If she has, it is unlikely that she could be hired by a home health care agency or become a certified nurses aid. Yet, the individualized care required of the COP program recognizes Denise as Ruth’s ideal helper as she has been steadfastly committed to Ruth and her rehabilitation for the whole past year. Denise had lived with her mother since moving to Milwaukee in 1990 until taking this job, but now she rents a small house from Jane just across the street from the Workmans. Jane has seen good changes in Denise since this started, “she has grown, believe you me. She has grown. [Laughing.] Yeah, I think she has. She had to start from zero. She has a job [now] she did not have. She was dependent on her mother;” and now she has her own place. Plus Ruth has learned to walk again because Denise believed she could do it.

In return, Denise feels like a foster niece to Jane who she likes and respects a lot. “We all connect as one, like a whole family, discuss things, anything and everything, and be shut case. And there is certain things that I do not talk about because it is confidential.” Denise facilitates Ruth’s independence by offering her choices in everyday activities, although she will not let her do “anything that will cause her harm.” Opinionated and vocal on others’ behalf, Denise is very protective of Ruth when they go out together. She values having Jane and Ruth’s trust; she moves about freely in their home to do whatever Ruth needs. She and Ruth discuss current events, mutual interests, and future plans.

So, while Denise has promoted Ruth’s recovery, Jane has promoted Denise’s independence too. Jane’s friendship with Denise’s mother partly facilitates their trust, just as other interdependencies within the neighborhood reinforce Denise’s commitment and reliability. Jane’s higher social status—being widely known and respected in both the black community and the larger community—may carry over to personal generosity and trust in her home, and it probably enhances Denise’s respect for and honesty with her. This mutual commitment and interdependency, Denise helping Ruth, and Jane helping Denise, is greatly facilitated by the COP program.

The other side of trust is the responsibility or indebtedness to the worker felt by a grateful client, which is probably most manifest in the way clients deal with personal things they know about their workers, which are often considerable. Joe Junkin, for example, knew that his female housekeeper was sick. “She just got out of the hospital. . . . She’s been at Mt. Sinai Hospital. She couldn’t eat. She come down here. She is taking pills what cost 59, 60 dollars a bottle. . . .” She hadn’t worked for a couple of weeks, and he was now holding her paycheck. Joe took the responsibility to complete the COP forms very seriously, “You see that slip? If I don’t fill this out, then they don’t get no money.” He had called this worker the day she got out of the hospital. Did he need something? No . . . “I wanted to tell her about the check. The check came yesterday. If those pills cost 60 some dollars a bottle, she must need the money. You know medication is still expensive.” His thoughtfulness in this regard reveals a great deal about the meaningful things he and his worker knew of each other.

Clients must negotiate many requests with their workers, but the clients whose workers are eager to respond are those whose first concern is for the worker, those willing to minimize their demands, to take turns “getting their way,” who give as well as accept help. Trust goes both ways.

C. Reasons for Case Terminations

Independent homecare work appears to be subject to the same occupational and longevity risks as other nursing work, in addition to other factors neither workers, families, or clients can control. But given the importance of familiarity and relationships to both elders and workers, the high turnover in homecare presents special risks in independent care arrangements. In this sample, over half of the elders (11 of 21) were no longer receiving the same care from the same worker by our second interview just four to six months after the first. In no cases did the elders no longer require care. Rather, the reasons for terminations typically involved circumstances beyond anyone’s control. Each arrangement was typically complicated by changes not only in the client and the worker, but sometimes in other workers, or in the client’s family members as well.
Hospitalizations and death are two continuous threats to the stability of caregiving relationships with frail and ill elders. In this sample, by our second interview with the workers, one client had died and two were temporarily hospitalized, but their workers (who were friends, and no longer being paid) were still hopeful of continuing with them.

Workers’ own health problems also necessitated terminations, or at least temporary reassignments in other cases. Mr. Junkin’s 72-year-old housekeeper, who had only casually mentioned having cancer at the first interview, was hospitalized and unexpectedly died. Two workers delivered new babies; while on unpaid “maternity leave” one had a friend temporarily cover her case, but the other was “let go” by the couple she cared for. (Given the long-term nature of some relationships, it is not always clear when independent care has “terminated.” One male worker, who looked after four elderly ladies in his neighborhood, had been terminated by the COP case manager from one of his two paid cases because this client now required personal care. But he continued to help out around her home without pay after a female nurse began providing care.)

At least two terminations directly highlight the “cost” to workers of a consumer-directed care program. One worker, depressed over her husband’s recent death, realized that caring for the developmentally disabled elderly woman in her adult foster home was too stressful when her client’s case manager, in consultation with the client, moved the client to another foster home. The worker lost the income of $1300 per month and at first did not believe the client had really wanted this. This client had limited competence so the extra support of the case manager had fortified the client’s interests. In retrospect, the worker also acknowledged that the transfer was “probably for the best.”

The second case illustrates that client and family empowerment takes precedence in COP. The displacement of workers is not uncommon, after all, as family carers, especially those living with the client, exercise their prerogatives to “take over” care when circumstances allow or even demand it, as in the case of the Witt family.

**The Witts: Low-Income Family Caregivers with Real Choices**

Molly Witt, age 48, has never been married. She “fell into being the family caregiver” when her father became ill in 1982; she was just 33. After his death a year later, Molly’s mother, Dorothy, needed help, and in the ensuing year, her mother, then 65, was hospitalized seven times for heart bypass, cataract, and bowel surgeries. Molly continued living with her mother and older sister, and the three of them eventually moved into their present apartment.

Fourteen years later, Dorothy, age 79, has had a series of mini-strokes. Molly has become the full-time family care manager as well as breadwinner, monitoring all her mother’s medications, preparing meals, and keeping her clean, plus looking after her sister who, while similarly devoted to caring for their mother, is developmentally disabled. Molly knows she can handle it, but is resentful that, as the second youngest of the family, her four siblings do little to help.

Molly worked full-time as a grocery checker for four years, earning $6.20 per hour, until her mother started needing more help. The family began paying a care worker privately before they got the present worker, Angeline, a year ago. Shortly after that Molly cut back her employment to part-time. They began receiving the COP payment in July 1996, after Dorothy had been disabled with Parkinson’s and Alzheimer’s for over a year.

Because Dorothy has “her good days and bad days,” which are very taxing emotionally and physically on those around her, Molly feels very responsible for her mother’s care. “It can be very monotonous and you do resent it once in awhile. Human beings do. But that’s the time you have to really, really remember, and think, if I’ve ever been through a test in my life, this is it…”

Responding to her mother’s need to go to the toilet several times a night, Molly rarely gets a full night’s sleep. She is always tired. “When I’m done with my job, I come home and have another. There is like no in-between time.” Very grateful to have had Angeline for the last year, Molly believes the relationship between her mother and Angeline is remarkable. “Angeline is a gem, she is a real gem. My mom connected with her right off the bat. She was just, it was like you either do or you don’t kinda thing, and we were fortunate. I trust that woman completely. She’s just become a mem-
ber of our family. She’s been a better support for me and has done more for us here in this household than my family has. “That woman is a rock for me.”

Molly especially values Angeline’s intuition and hard work. “She’s a real treasure” (p.20). “Every health care worker should be as conscientious as Angeline is about her job. She is a very clean person; she does things you don’t even have to ask her to do. She just automatically does em.”

Ten months before our first interview Angeline had taken over this job from her cousin, shortly after which Dorothy became eligible for COP. Age 49, separated from an abusive husband, with five grown children and 15 grandchildren, Angeline had completed a two week homecare training course with Interfaith just before taking the job. Despite years of factory and hotel housekeeping employment, and lifelong experience caring for her own family, Angeline has no formal health care experience. Like many black women her age she has hypertension, diabetes, and no health insurance. She also has a painful wound in her leg where her husband stabbed her three years ago. She relies on a local public clinic for her medical care.

From the beginning COP paid Angeline $9 per hour for 27 hours per week and Molly paid for up to 12 hours more, depending on her own work schedule. Angeline could have taken on more clients, but she became quite fond of Mrs. Witt and her daughters. Shortly after being hired, she moved from Milwaukee’s inner city to their Southside neighborhood so she could walk to work and be on call. She shares a two-bedroom apartment with her youngest daughter who works full-time at a nearby university. Angeline’s schedule was unpredictable from week to week, depending on Molly’s work at the grocery store.

Within a year, COP had increased Mrs. Witt’s care level to 40 hours per week, giving Molly, then constantly exhausted, a real choice between working and staying with her mother full time. Then in spring 1997 the grocery store closed and she lost her job. Her decision was settled. Rather than seek another, she decided to accept COP’s $1500 per month and become her mother’s full time caregiver.
D. Behavioral Problems and the “Social Rights” of Difficult Clients

The latter two examples highlight an aspect of consumer-directed care seldom mentioned in American discussions of client autonomy, but significant in the more “rights-conscious” British policy research literature. Barnes (1997) and Morris (1993, 1997) both question whether consumer-directed care models adequately protect the elderly client’s “right to be cared for.” Relatives’ and workers’ descriptions here of challenging client behaviors remind us that all elders are neither sweetly compliant, nor equal in their demands. As Morris (1997) points out, the self-direction model of care requires a kind of “co-production” of care wherein the consumer works as hard at facilitating the care as does the worker. The “difficult client” and their family members who cannot conform to the emerging consumerist, self-help expectations that they share responsibility for care pose a serious dilemma to a care system charged with providing them appropriate, adequate care.

Might a consumerist norm actually violate this client’s right to have care at all? What happens to the difficult client for whom no one wants to, or is willing to, work in a free market in care? Several of these independent care cases highlight the need for both male and physically strong carers to lift heavy patients or restrain physical acting out. Yet, few men enter this field, and women who do experience a high rate of work related injury. Indeed, by objective criteria this labor market appears to have a high proportion of marginally qualified home care workers, which is not to say that either service users were dissatisfied with them or that the workers were incompetent (consumers learn to be satisfied with what they get). Rather, relying on a consumerist model creates a danger that society as a whole may easily abdicate its responsibility for the assurance of adequate amounts of appropriate care for some elderly clients. And clients who are difficult to serve are then more likely to be blamed for their own problem.

While only a couple serious behavioral challenges occurred among the cases sampled here, nearly every experienced worker described to us clients who had tested their personal or professional limits in the past. Workers’ limits, which in private care are often personal rather than professional, ranged from being bothered by profanity or smoking in a client’s home, to being emotionally shaken by teasing, threats, sexual suggestions or behavior, aggression, or literally physical assault. Sometimes it was only because of workers’ personal sense of responsibility, knowing they “could take it,” and their concern for “their” patient, along with their need to keep the job, that prevented their walking out and abandoning a patient.

Interestingly, the market does not necessarily react in accordance with the difficulties of serving a particular individual. The most “difficult” clients do not necessarily have the most difficulty finding helpers to hire. For example, Joe Junkin, the gruff bawdy black man who told our researchers he “carried a piece” and had pocketed a knife at the beginning of the interview, had two faithul workers who kept his apartment clean, by his standards at least, and were solicitous of him. Other extremely poor clients, even ones who required heavy care such as Mr. Willis and Mrs. Bell, also had devoted workers.

Yet, one middle class white woman was possibly the most “challenging” client in this whole sample.

Mrs. Sharp’s Struggle to Maintain Control

An 88-year-old former accountant (who managed “five girls in an office”), Mrs. Sharp had a series of falls beginning eight years ago that broke her hip and eventually necessitated a total hip replacement. Since then she has suffered severe arthritis in her back, has had several cardiac surgical angioplasties, and been treated for breast cancer and a nasty infection in her arm. Blind in one eye since a childhood accident, she had cataract surgery in her good eye last year. She gets around with a walker now, and requires only light care, regular help with dressing, laundry, shopping, and washing her hair. She gets 97 hours of care per month, about 24 hours per week on 5 days, for which Grace is paid $10 per hour.

She was considered very difficult to work for, however, by both her daughter and her worker. When asked how she feels they get along, she states that she is a “speak up person” who simply “corrects” the worker when she needs to, even though in another breath she admits these are not very significant things. “I want it (done) my way because it’s my house.” She gave explicit examples of how Grace irritates her when she does things around her home. She does not ask her to make rice anymore, for example, “because it is very hard for me to convince her that rice has to be measured out and the cover has to
be left on through that time because if it isn't then the kernels will start to get mushy. And I don't like mushy kernels. . . Some people like it that way and they like it to be more creamy and mushy. . . They like it that way! That's the way they cook, you know, and so I don't even ask her to do it that way anymore."

And "I have to tell her how to dust. She can clean all right, but she is just in the habit of cleaning out the top of things, I guess. The tops of the cabinets get all dusty and I don't like that. You have to take a damp cloth to clean that because you do, and I have to explain that to her." She does not fold Mrs. Sharp's nylon stockings the way she wants them. Mrs. Sharp has expended a good deal of effort “correcting” Grace, but admits “You don’t change a person completely. You make allowances for everything.” Asked what Grace is really good at, she responds. “She is a compassionate person. She tries real hard and tries to satisfy you. She really means well. I don’t want someone who is going to argue and say I like to do it my way. You know, cause I don’t want that unpleasantness.”

Mrs. Sharp admits she is receiving good care, but not excellent care because she has fallen at times when Grace was not there. If she needs more care, Grace “will have to provide it because she is trained to do that.” Besides being fastidious about cleaning and demanding about how her food is prepared, she expects her worker to accompany her to lunch at restaurants, to do errands, and to “chauffeur” her to various appointments “on demand.” She is waiting now for a good day because “I have to have my windows cleaned, they are really bad, you can hardly see through them. We were waiting for a nicer day you know.”

But the most difficult thing may be the way that she comments, through innuendo really, about Grace’s character. “She’s probably done a lot more (cooking) in her lifetime because she’s been married a long time. But what she has shown me is that she’s not a cook.” And, in fact, she’d love to have helpers there every day of the week, even though she manages now to cope over the weekend by herself.

Indeed, the sheer variety of the expectations held by some clients and the enormous needs of others is what makes a consumer-directed program like COP appealing, especially to government seeking a flexible way to accommodate complex needs. This sounds like a great way to tailor the care needed by elderly disabled persons, while still allowing the client power to manage their own day to day activities. The only resource that needs to be really flexible, then, is the personal care worker whose strength and capacity is available for hire.

But, is this realistic? Is the appropriately diverse pool of workers really available? And is it fair to the workers to expect them to meet such a huge variety of needs that arise? To determine this we must examine the workers’ circumstances as closely as the clients’.

V. THE PROCESSES OF COP HOME CARE: WORKERS’ NEEDS, WORKERS’ SKILLS

A. Workers’ “Private Lives”

1. The Prevalence of Trauma and Injury among the Workers

Perhaps because we were mostly white and relatively advantaged ourselves, our researchers were deeply impressed by the high proportion of COP workers sampled who had known a great deal of hardship in their lives. Some of this was related to the workers’ own health problems or those of their families (noted above), which seemed to have made them especially sensitive to others’ needs. But hardships went much beyond health problems. These difficulties can be distinguished by the ones workers had experienced growing up and in the past, and ones that still presented challenges to their personal safety, long term security, and employment prospects.

a. Past Injuries and Disadvantages. Several homecare workers in this sample had been orphaned or left to be raised at an early age with adoptive parents, grandparents or other relatives. This was especially true of African-American women, most of whom had been born in Southern states (Mississippi, Missouri, Arkansas, and Alabama), whose parents moved North before they did. Many, both black and white, were from very large families, some with ten and even fifteen siblings; family histories of extreme hardships, parental separation, absence or death, and alcoholism were common. Many of those who were born early in such families had had a lot of responsibility as children for their younger siblings, and had then had babies of their own at an early age. Some had had their first child in their early teens. In addition, while growing up, many, especially those from the rural South,
had done very hard work: working the fields, picking cotton, and otherwise helping their mothers work and care for family members.

In a couple of cases women had probably been raped at an early age and had learned to expect very little from life. The scars remain in the risky and self-destructive behaviors in which they still engage. Carrie began drinking at 13, had her first baby by 15, and only achieved sobriety at 37. At least a couple of other workers suffer from depression or emotional instability. As noted above, 38 percent of this sample never finished high school and possibly had learning or reading difficulties. Six (28 percent) had never married. Both black and white workers had experienced single parenthood, and several had depended on AFDC for at least a few years to raise their children. Presently many workers “appearance problems” reflect their lifelong feelings of shyness, lack of confidence, and non-assertiveness. A few have speech impediments or speak with such distinctive dialects that their pronunciation was difficult for the interviewers to understand. Several have serious dental problems, either missing teeth or ill fitting dentures which make them feel inhibited around strangers. And many struggle with serious weight problems which complicate the array of complex medical difficulties noted above.

b. Current Injuries, Experiences of Violence, and Other Difficulties. The other aspect of life for many workers, especially those living in inner city Milwaukee, is the daily probability of their experiencing violent or otherwise tragic events or knowing persons who have. One worker told of how violence in the neighborhood around 14th and Hadley had increased in the past two years, and of a youth being shot two blocks from her home. Many had themselves been assaulted in the past. Angeline’s first husband had been murdered in a park near her home, and her later husband had beaten her, permanently damaging her knees.

Living with Neighborhood Violence and Personal Losses
Gloria’s soft-spoken and gentle manner belies her inner strength. Now age 46, she lives with her teenage daughter in a Central City neighborhood near Locust Avenue. Having done personal care work for 13 years, she managed to move from her sister’s home into her own place three years ago. Working 40 hours a week for one COP client at $7 per hour, she grosses about $1210 per month, her only income, and has difficulty making ends meet financially, partly because of a $2,000 medical debt she is slowly paying off. She simply has no reserves if something unexpected comes up. She recently missed a relative’s funeral out of town because she could not scrape together the bus fare.

Gloria needs a phone because of the crime in her neighborhood. She worries about her daughter who one day called her at work to report somebody was shooting behind their house. Another time a neighborhood alcoholic built a fire on a grill on their front porch. Her door has been knocked from its hinges, and her pantry window has been broken. But even more stressful to her is a series of losses she has experienced in the past year. Her 25 year old cousin was shot and killed last summer in a drug related situation. Her 50 year old sister died last December of emphysema, and her 30 year old niece died in March. And she recently learned that another sister has breast cancer and needs to have a mastectomy.

Some workers have seen close relatives and even their children sentenced to prison. One worker was preparing for her son’s release from prison where he was serving time for a drug conviction. Another, whose own education and accomplishments were substantial, mentioned in passing that her son was serving a 33 year conviction for domestic violence. The crack epidemic of the last decade that had palpable damaging consequences in Milwaukee’s inner city has left its toll on many health care workers and their families.

2. Inadequacy of Compensation, Racial Disparities, and Workers’ Feelings of Being Exploited
This small, non-random sample of COP workers includes 15 black and 6 white workers, but comparison of the average hourly wages of these two sets reveals a troubling wage disparity. Black workers’ average hourly wages were $6.70 while white workers average hourly wage was $8.70.

As noted above, workers doing care work in this sample (at first interview) were making from $336 to $1224 per month in COP program wages, but hourly wages actually ranged from $5 to $11. While there may be many reasons for the disparity in this sample, this is a small and non-random sample from which we cannot generalize to the rest of the COP program. (Such an analysis would require a random sample of all COP workers’ wages.)
A few workers complained openly about conditions they experienced on the job, which were typically related to compensation and inconsideration by the employer. Tawana points to the problems for workers because the county allows family caregivers to subcontract with other workers. Tawana thinks that COP is paying the family she works for $6 an hour who, in turn, pay her only $5. She has complained to both her client’s son and the case manager, but has not yet resolved the situation. She feels particularly disadvantaged in these discussions because she needs this job so badly.

**Tawana’s Resentful Attitude: Marginal Assets, Entry Level Work**

Two workers we interviewed working for the same client were earning $6.50 and $5.00 per hour, one having been with the client for four years and the second for four months. Basically working for the client’s family, they are expected to arrange their own backup (replacement) if they have to miss a shift. Both enjoy being with the client who is totally paralyzed, bed bound, and unable to speak, the result of a stroke. Neither finds the job isolat-
ing or dull, but the worker on the night shift leaves directly in the morning for her day job, cashiering at a retail store.

The other worker, Tawana, is younger and paid less, working three days a week, taking home $320 per month. She feels she is not being paid fairly by the family. Thirty-six years old, Tawana suffers from hypertension, asthma, and knee and back pain due to being overweight. She has several missing teeth and a speech impediment, and recently served 15 months in prison for drug possession. She is highly motivated to do well now, however, knowing this job may be her last chance to “make good.” Working on earning her GED, she attends classes 15 to 20 hours per week.

Tawana has four children, ages 21 to 15, and often cares for her three grandchildren during the day; only her two teenage sons live with her. One of them receives $239 per month in Social Security, since his father is dead. Tawana herself receives $521 in SSI disability because of her feet, back and body pain, and obesity. SSI rules limit her from earning much more income than she does through COP, but her rent of $450 a month so, she says, “my whole (SSI) check take most of my rent.” Finances are tight with a lot of people depending on Tawana to keep it together.

Nor was Tawana the only worker on SSI who faced an “income trap” in being restricted in how much she could earn. Mr. Junkin’s male worker was also on SSI and was also limited in what he could earn. Consequently Mr. Junkin had two workers.

Another worker complained that COP did not pay her for many hours she worked after her client’s hospitalization for her stroke. For a couple of months, regular Medicare nurses came in to tend the patient, but Lilly felt her client still needed personal attention and housekeeping assistance. During these two months Lilly said that she worked 12 hours per day instead of her usual 4 (28 per week). “I was doing 12 hours a day for her. I did the floor two times a day. She had two or three therapists and nursing coming in, but I had a doctor’s statement saying she needed 24 hour care.” Lilly submitted a claim for these extra hours, but no additional hours were authorized while the nurses were coming. After that Lilly received a letter from the case manager saying, “Denied increase in service because of lack of cooperation of aide.” Ten months later Lilly was still arguing with the case manager that she should have been paid.

The Uneven Availability of Cars and Other Requirements of the Job

Workers who had cars sometimes used them to do errands or shopping for the client, and in some cases were expected to do so regularly. Indeed, none of these clients had cars that could be driven by the worker, and only 12 of these 21 workers had a car of their own. Some only used it to commute to work, and some of the others didn’t mind occasionally doing errands for their clients. A few also felt that doing errands and transporting the client was within the scope of the job. Vanessa would take her client to his favorite restaurant and leave him there, or occasionally have lunch with him; several took clients to doctor or beauty shop appointments. And no workers mentioned being paid for mileage or out of pocket expenses.

Grace, however, who was paid $10 per hour, felt that her client, Mrs. Sharp, was overdoing it. In addition to expecting Grace to take her to doctor and beauty shop appointments and shopping, Mrs. Sharp expected Grace to accompany her to eat lunch at restaurants nearly five days a week (paying for her own out of pocket). Mrs. Sharp’s daughter, who with a friend and another homemaker, was her COP caregiver for two years, acknowledges that her mother can be demanding and inconsiderate of others’ feelings. She “likes to have a lot of people serve her, so she was very willing [to have help].” “My mother is hard to work for, especially if you are very close to her.” She adds, “She has some depression, I think mostly because she can’t do what she wants to do, but I think that comes with age.” What bothered Grace most was the feeling that frequently her client bought items and had her return them simply to create work for her to do, to keep her busy.

3. Inadequacy of the Fringe Benefits of the Job

For many workers independent care work simply does not provide vital security: health insurance, a pension, even Social Security, not to mention paid vacation, or sick days. For some this is not a big issue because they have other resources, jobs or household members they count on for financial support. But most do not have such resources.

The Urgency of Workers’ Health Problems, Lack of Health Insurance

The urgency of some workers’, and their children’s, health problems, tends to push a high percentage of
women into very stressful, but isolating alternatives. Which is to say, even the fondest relationships can be struck down by the precarious conditions of the work. Indeed, precarious conditions sometimes predominate for all three stakeholders in these three way relationships, everyone's focus becoming quite short-term: paying the next bill, moving, getting a bus to work, “just” getting the telephone service turned back on.

Fundamentally, these are workers who have little personal financial security. Few had any savings at all, and most relied on other family members or friends if they could when faced with an emergency. A remarkable share of their financial stresses come from unanticipated, unaffordable, and uninsured medical expenses, as was noted in section IIIB above. These “personal problems” are well known to the consumers, but together they are not heavily resourced to assist each other.

A. The Workers’ Challenges in Providing Independent Care

1. Identification with Caregiving as a Career

As they talked of themselves and their motivations for doing homecare work, one of the most impressive aspects of some COP workers was their strong sense that caregiving was much more than a job. For some it was obviously a career choice. For them a strong satisfaction of the work was having close and long term relationships with clients. They compared it to working in a nursing home or even a home care agency and felt they preferred this because they had more control of the job and their own time.

The two workers who had taken the two week courses conducted by Interfaith and Family Services to become supportive homecare workers had learned techniques that gave them a sense of professional competence, along with reinforcement of their own strongly held values. Many of the workers commented on things they had learned from the recent training they had been required to take by the Department on Aging, such as techniques for lifting and transferring, bathing, and making nutritious meals.

A striking feature was the high proportion of workers whose own mothers and other female relatives had worked in cleaning or housekeeping jobs, or in nursing or other health professions. Nearly all had cared for younger siblings growing up. Many had learned health care skills from nursing members of their own families, typically siblings, sick or disabled children, or an ill or dying parent. Meg notes, for example, “I have three children, one who became insulin dependent when he was 8. In that same period, my father became gravely ill, and from his illness and being with him during the last six months of his life, I saw the need for and the benefits of helping people who are ill.” Others like Meg and Angeline, who had taken up PCW work “later in life,” felt caregiving experiences had transformed their lives.

Meg gave up a thirty year career in sales to embark on this new career in personal care, but says that by comparison this work “is good for the soul.” Angeline did the same after nursing several elderly relatives and surviving several personal losses. She likes the feelings of goodness and altruism she gets from doing care work. Many workers identified strongly with their religion and are active in church congregations; one is a part-time minister. Religious faith is a source of strength and perseverance for many; they talk about that sincerely and derive great comfort from being able to share that faith with the older persons they serve.

Not all workers had felt changed positively, or even changed at all, by doing home and personal care work, however. As noted above, most of these workers had only one client, and many of these relationships had existed long before the COP payment was initiated. A few workers showed distinct signs of depression and listlessness. Carrie says simply it “gives me something to do,” and Denise appears to suffer from mood swings some of the time. After her husband passed away, Mary Baker, who provided adult foster care in her home, began to resent the emotional burden of the two developmentally disabled clients she had cared for five years. Her need to take time for herself to grieve prevented her from continuing to extend the empathy she had previously given generously.

Depending on the kind of work they had done before, some workers are simply matter of fact about caregiving. They provide only minimal personal care and tend to take the same approach to care work as to other work they have had. Personal relationships may be rather superficial, and the job just pretty routine, fitting in around their busy lives. Lilly, who cooks and looks out for a neighbor in her building, enjoys being with her, but basically approaches her client’s apartment as she approaches the other cleaning jobs she has held throughout her life: just dig in and do it. Most of our conversation about her client was about bathing, scrubbing, and cleaning up, because this client, who has difficulty controlling her mouth because of a stroke and has urinary incontinence, is “a constant dribbler.” Having covered her own furniture with dry cleaning bags to protect it, Lilly
welcomes her client to watch TV and eat in her apartment, and the two women, both divorced, keep each other company. For the worker caring for Mrs. Bell on the night shift the job is mainly convenient because it accommodates her day job. Like other women who have raised children and cared for, and lost, a spouse, at age 52, this worker likes living “on her own.” She works long hours to have enough money to enjoy it. Some of these “non-career oriented” care workers even emphasized that they would not do this job if it required extensive personal care, since they lacked a tolerance for “bed and body work”. They didn’t mind being responsible for housekeeping, cooking, companionship, and tending, but if the client came to require more skilled care, other care providers will be needed.

2. Handling Difficult Clients and Maintaining Good Relations with Clients’ Case Managers.

Many workers talked of other difficult clients they had worked with in the past. It is mainly from this experience that PCWs have learned to be effective in dealing with difficult clients. Most older African-Americans rarely mentioned having experienced racism in their care work, but younger workers were more willing to do so. While no white workers in this sample had black clients, five black workers currently had white clients. Like several of these black workers, Vanessa has worked with both male and female clients, and all races and backgrounds. She was comfortable addressing issues of racism directly.

Vanessa’s Education:
Encountering Institutional Racism, Maintaining Balanced Relations with Clients

The youngest worker in this sample, a confident 22 year old African American, has been doing independent personal care for three years. A Milwaukee resident, Vanessa graduated from an excellent suburban high school and went right on to college. Through a high school friend who is a DOA case manager, she began getting referrals to work with older clients. Vanessa had been very close to her grandfather who died several years before of cancer; she found she enjoyed work with old people and it turned out to be a good way to work her way through college.

She was warned before she took him that her first client had attacked a woman before her. Vanessa told this client right away that she was there to help him, to do his laundry and take him out, but she was not going to play games with him. After several months on the job, when he began pestering her to bathe him, she said no and asked his case manager to find him another worker. They found a male PCW to take over for him after that. She has since found she can usually work things out. Now she is especially fond of her Hispanic male client who, estranged from his daughters and ex-wife who lives nearby, “has no one else.” Bright and articulate, Vanessa works hard and welcomes challenges. Nearing her last year in college, she schedules her work around her classes; she hopes now to become a physician.

Vanessa really values her independent care work and the relations it allows her with clients. At one point she thought about getting certified, so she attended an orientation for potential CNAs at a highly regarded local nursing home. Up until then, she says, she’d not realized the discrimination against black females in health care itself. There were 20 to 25 black women in the class, “so the only white woman really stuck out.” The message she felt was that only black women could be expected to clean up after other people. In other words, men and white women had other ways of making money. She was deeply offended by this insinuation, and left after the first class, determined never to go back. She is glad she has not had to.

Some workers were not aware of the source of their paychecks. One confusing factor is that the return address on the check envelopes is that of the fiscal intermediary rather than the Milwaukee County Department of Aging. In addition, not all workers have regular contact with the clients’ case manager at the DOA. And, as noted above, checks were sometimes sent to clients’ homes and delivered to workers by the client and in other cases sent directly to workers’ homes. However, some workers were very knowledgeable and resourceful about the DOA. At least one worker had called one case manager so often to complain that he no longer responded to her calls. Clearly case managers are in a position to advocate for good, reliable workers, since within some parameters they actually recommended and negotiated workers’ wages.
Workers with experience and good relations with clients were in a better position to negotiate for a higher wage.

Since most workers had only one client and had no previous experience with the COP program before their present client, most in this sample picked up their check at their client’s home. They had little if any contact with the case manager. However, at least one worker, distrustful of the client’s family, had arranged to have her check sent directly to her own home. And a few others received their checks directly from the family caregiver who actually received the DOA payment. There seemed to be wide variation in these patterns, but clearly workers with infrequent contact with the case manager were left much more on their own if difficulties arose with the client. Many workers were apparently quite comfortable with this and negotiated almost everything directly with the client.

3. Private Work, Private Burdens

Having sole responsibility.

At least 8 clients had family members to whom their workers could also turn for help, but in 11 cases the client had no relatives or friends, so the worker had no one to discuss the client with except possibly the DOA case manager. Workers took an extraordinary amount of this responsibility on themselves, especially those who had “carried” a client for a year or more. For example, Mr. Willis’ regular worker had cared for him for 7 years “with only two vacations.” His only family was an ex-wife who called about once a year. And Carrie, who lived with Ms. B, was constantly responsible even though her husband and daughter helped sometimes. In both of these cases where workers co-resided they provided vital routine care every day of the week without a break, understanding their payment to be for services performed 7 days a week. Unless the worker-family caregiver relation was a fairly balanced one, with a lot of reciprocity in acts or words expressing mutual respect, there was a tendency in most cases for the worker to gladly defer to a relative. Less empowered workers are not likely to talk freely about their own personal needs; some never did so. Occasionally it was remarkable how little relatives knew about the worker’s personal situation or the difficulties presented by the client. For example, Mrs. Sharp’s daughter knew very little about Grace who cared for her mother. Even though she acknowledged her mother was difficult to work for, she had evidently never admitted this to Grace. It makes sense that a
lot of personal chatting between a client and worker is about each other’s families, but only if their relationship is a balanced and respectful one. Sometimes family members knew far too little about their worker because the worker was afraid to reveal information she worried could literally be “used against her.”

**Having to arrange backup.**

Tawana resented being expected by the family that she worked for to arrange other coverage if she had to miss work. She was actually luckier than many workers because Mrs. Bell had five other workers with whom Tawana could have traded shifts, although apparently she had little opportunity to meet them. Many workers with substantial responsibility also knew few other personal care workers. Consequently many relied upon their own daughters or family members to help out and/or fill in for them, as did Mr. Willis’ worker and Carrie. Vanessa, for example, took her father with her to see her client in the psychiatric hospital. Angeline had found the Witt family through her cousin, and was occasionally relieved by her daughter or the cousin. Clients who had other friends and visitors who could help out were less burdensome for workers in terms of the personal commitment and sense of responsibility they required because responsibility was shared.

**Time pressures and working “on your own time”**

A distinct attraction of COP work for workers is that the time workers and clients can enjoy together is usually less pressured than other health care work. However, the five who worked 10 to 15 hours per week and did not co-reside with their client typically had a lot to do and sometimes were stressed by their clients’ needs to “just talk.” They had been assigned specific medically-related, personal care or housekeeping tasks which took priority. Some workers were more comfortable cleaning, doing laundry, and cooking than talking anyway, but others simply were pressed for many reasons to do most of their work “on the run.”

Valerie, for example, who was 24 years old and expecting a baby, worked 15 hours per week, driving from one side of Milwaukee to the other to work three hours a day each weekday. She helped an elderly couple both bathe and dress and did general housework. In fact, however, when she was alone with him, Mr. K made sexual comments and advances that made Valerie very uncomfortable. Perhaps unsure how to handle this, Valerie never talked to the family about Mr. K’s behavior. Mrs. K, meanwhile, complained that she never knew when Valerie would arrive and that Valerie never had time “to just talk. She comes here and always runs first to the basement to start doing laundry.” Anticipating the birth of Valerie’s baby, Mrs. K told the researchers privately, “oh, we can’t have a baby around here;” but it was probably her lack of closeness with Valerie in general that led to her not inviting Valerie back after the baby was born. Apparently both parties were relieved that Valerie’s pregnancy put a natural termination to her employment. Other workers seemed to find the time for intimate conversation even while busy with housekeeping, and especially while dressing and helping with personal care. In COP the workers’ independence and flexible schedule certainly facilitates partners in care communicating when they want to. Working as little as four hours per day worked found time to share meals with clients and talk. Most felt strongly that making time for talk was important for their client and thus important to them, even when they had little time available. Paige, for example, has helped 60 year old Mrs. Bono who has multiple sclerosis for ten years, and never for more than ten hours per week. Working her other job for a home health agency, typically seeing 2 to 6 other clients a day, Paige’s day is “on the run” most of the time. Mrs. Bono and her husband are both immigrants and Mr. Bono speaks very little English. They are lonely and frequently ask Paige to “make us last” so that she can relax, sit and drink coffee with them. Paige described the careful regimen she reinforces for this couple, keeping Mrs. Bono’s spirits up, and constantly encouraging her to sit up and do as much as possible for herself. Paige is a well trained C.N.A. whose many patients typically have medically complex needs. She has studied the psychological and emotional aspects of MS and works carefully at setting little goals with the Bonos. Balancing her own mind-boggling daily schedule, Paige is a life line for many of her clients, but has special fondness for this couple. Paige described the careful regimen she reinforce for this couple, the Bonos, which took priority. Some workers were more comfortable cleaning, doing laundry, and cooking than talking anyway, but others simply were pressed for many reasons to do most of their work “on the run.”

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C. Real Flexibility and Authentic Choices

This research has permitted extraordinary glimpses of how women wrap their lives around the
sometimes very limited options available to them. There is no doubt that this consumer-directed care model offers a flexibility to participants that does not exist in the traditional agency home care model. Another reading of the Witt case, however, illustrates both the strengths and weaknesses of direct payment for independent care. The “interests” of the caregiver daughter, Molly, and the personal care worker, Angeline, are not the same. One person’s strength can fill another’s need, but in return, one’s advantage can also be another’s disadvantage as needy people come to rely heavily upon each other.

The Interrelatedness of Client, Family, and Worker Quality of Life
An unusually good relationship existed between Mrs. Witt, her daughter Molly with whom she lived, and Angeline, the worker. Angeline, who is black, moved herself and her daughter into the Witt’s mainly white southside apartment complex soon after she began working for the Witts. Angeline didn’t have a car and was fed up living in her central city neighborhood anyway—her first husband had been murdered there, and she had been abused and attacked there by her third husband. Then, after 8 months, the county approved an increase in Mrs. Witt’s hours of care from 24 to 40 per week. This happened just about the time that Molly lost her part-time, $6.50 an hour job as a grocery cashier. Exhausted anyway from doing two jobs, Molly decided to become the paid carer herself. By the second interview she was earning nearly $1500 per month less taxes as her mother’s COP worker. She would then hire Angeline when she needed relief. As a result of Molly’s decision, however Angeline lost a full-time job. Indeed, becoming abruptly unemployed may have been temporarily disastrous for her, but she expressed no resentment or reservations about this, despite the new uncertainty of her life and her schedule. She relied on her children for several weeks until she found a good referral source for new clients. A resilient, resourceful networker who loves her new professional identity as a caregiver, Angeline volunteered at Interfaith, and quickly landed several new client referrals. She soon began working for an elderly couple back on the Northside, de-

This woman (right), who has multiple sclerosis, and her husband; have relied on daily visits from a faithful PCW for over 10 years.
spite having fled that neighborhood before and even though the new job, again several miles from her home, requires another hour long bus ride.

The respectful relationship between Molly and Angeline continues to be important to them both. Angeline continues to be “on call” for Molly who now pays her out of her own COP reimbursement for the hours she works. Angeline hopes someday to become an LPN. She says her children call her the “Speed Racer,” because she is always in a hurry, but Angeline feels that care work has given great meaning to her life. “I’m—you know how squirrels do? They store up nuts and stuff for the winter? Well, I want to do all I can while I’m able to do this, you know.”

VI. DISCUSSION AND CONCLUSIONS

A. Flexible Benefits and Relations that Work

This study has provided a rare glimpse of the subterranean side of everyday life in Milwaukee in the homes of frail and disabled older people who “don’t work.” In this study both COP Program users and workers have expressed great satisfaction and high praise for the COP program and the flexibility and alternatives it allows them relative to one another. While many older service users are frustrated by their inability to perform daily activities by themselves, they believe their situations are better now than before services were provided. For older clients who have them, family caregivers also express fatigue because of the work still required of them, but they eagerly admit they couldn’t provide care alone now without the COP program worker or funding supporting them. For them COP’s consumer-direction philosophy fortifies their strengths, making them partners with their loved ones in managing care they understand better than anyone, and within fiscal limits, helping them make their own choices. All the clients and families we met were reasonably competent to make decisions and benefited greatly from the discretion, dignity and resources COP afforded them.

Workers were also content with the flexibility COP gave them and the judgements they were authorized to make, feeling in most cases that this was a pretty good job. A few workers would like to work more hours, but have little access to other clients. More than half of these workers saw COP as their way of helping a friend, however, and expressed no intentions or desire to make homecare their career.

All this flexibility amounts to a benefit for clients that is not really “fixed” and the assignment of a worker whose time and duties are not tightly “fixed” either. In insurance a fixed benefit is one that is equivalent to an assurance of a certain amount of something valued when needed, or a guarantee of provision of a certain procedure, or coverage of a defined loss. In COP the benefits are “tailored to fit”, determined at the discretion of a case manager who consults with the patient and with experts, but has the responsibility to assess client need rigorously and fairly and design a plan to meet these needs. The determination to pay a certain amount to a worker is not “fixed” either. The DOA has struggled to set parameters on hourly wages for several years without ever setting hard and fast rules. After all, it would be unable to accommodate the individual needs of all who qualify for care if it had specific prescriptions!

B. The Multicultural Context and Structural Disadvantage

Even with a limited number of cases, this study has highlighted aspects of the urban environment that both facilitate and impede the maintenance of independence by elderly disabled people, by limiting the accessibility of independent workers to elderly clients needing care.

A key aspect is the simple geographic residential dispersion of clients and their workers as can be seen on Figure 3. The dark area highlights the location of the central city in which 90 percent of the residents are African-American; the outer gray area surrounding this is where households are 50 percent or more African American. This map reflects the legacy of racial segregation in housing that still exists in Milwaukee. Put simply, black people, including homecare workers, especially those who are poor, have fewer options regarding where to live than do white workers, especially white people with higher incomes.

Figure 3 displays the approximate address of client-worker pairs in this study. As noted above in section III, of all 21 cases in the sample, the black clients (n = 10) were all served by black workers and in most cases their workers lived close by. However, the 11 white clients were served by black workers in 5 cases, nearly half of the time. White clients were half as likely to have a white homecare worker, and, partly as a consequence of geographic segregation and thus travel distance, much less likely to have a worker who lived nearby.
This segregation largely explains the high proportion of black elders who have black workers, since many black workers also live in the central city area and their relatives and friends are more likely to know one another. Inner city residents are also more likely to rely on public transportation, but workers serving clients living in the outer areas of the city are more likely to own cars.

Finally, a huge number of welfare policy changes have occurred in Milwaukee since this study began in January 1997. Nationally Wisconsin has become the epicenter of welfare reform, with precipitous declines of AFDC enrollments in the past eight years. AFDC enrollments in Milwaukee dropped from about 100,000 in 1990 to about 9,000 on W-2 in 1998. In 1996 Milwaukee County closed its only public hospital; in 1998 it adopted a plan to disperse the care of low-income adults qualifying for the General Assistance Medical Program (GAMP) to a dozen local community clinics. Despite the county’s claim to have maintained its effort, for many low income workers, the GAMP program is still a secret. In addition, the child care benefits promised W2 participants have not materialized; child care access problems featured widely in the press, caught up in controversy through most of 1997 and 1998.

The two pregnant workers in our sample had their deliveries paid for by Medicaid Healthy Start, and 6 of the 7 workers who have young children relied on public programs for their health care. Perhaps of greatest concern will be the implementation of the 1998 state legislation requiring criminal background checks on caregivers (Chapter 50 Uniform Licensure) which could make persons with criminal records ineligible for work with the elderly. Although the implications of this law are unclear, it may compound the problems of workers with criminal records by denying them employment and could further limit the health care labor pool, making familiar and competent workers even more difficult to find.

C. Strengths and Limits of the “Consumer Options/Consumer Direction” Approach.

Table 8 summarizes the varied issues identified in this investigation as strengths and limitations of a consumer directed care program. This list is arranged, as was this study, to identify the differential needs and “interests” of the three key stakeholders in independent care arrangements. Central in this conceptual model is the valuing of care in terms of it being an organic whole, a process involving committed partners all nearly equally invested in making the arrangements for care “work.” Central to this framework is the identification of the different “interests” of the three parties directly engaged in care: the client, family, and paid worker.

<table>
<thead>
<tr>
<th>Strengths of Consumer Directed Care Approach</th>
<th>For Clients</th>
<th>For Family Carers</th>
<th>For Workers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Flexibility</td>
<td>Choice (usually) in whether to be paid carer</td>
<td>Choice regarding which family member will be paid</td>
<td>Flexibility regarding own schedule</td>
</tr>
<tr>
<td>General satisfaction</td>
<td></td>
<td>Choice regarding which family member will be paid</td>
<td>Discretion, ability to exercise own judgement</td>
</tr>
<tr>
<td>Filling gaps</td>
<td></td>
<td>Authority to negotiate with worker(s)</td>
<td>More work =&gt; more pay</td>
</tr>
<tr>
<td>Control, for some</td>
<td></td>
<td>Familiarity</td>
<td>Time is slower, has different meaning</td>
</tr>
<tr>
<td>Ability to have familiar helpers, usually</td>
<td></td>
<td></td>
<td>Opportunity for close relationships</td>
</tr>
<tr>
<td>Maintenance of daily routines</td>
<td></td>
<td></td>
<td>Opportunity for obtaining entry level experience</td>
</tr>
<tr>
<td>Allows intimate/long term relations</td>
<td></td>
<td></td>
<td>Ways can be found to “supervise” work</td>
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<tr>
<td>Time is less pressured compared to agency care</td>
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<thead>
<tr>
<th>Limits to Consumer Directed Care Approach</th>
<th>For Clients</th>
<th>For Family Carers</th>
<th>For Workers</th>
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<tbody>
<tr>
<td>Heavy dependence on one worker</td>
<td>Need to arrange backup</td>
<td>Inexperience managing employees</td>
<td>Need for backup coverage, many can’t arrange it</td>
</tr>
<tr>
<td>Waiting list = 2 years (+)</td>
<td></td>
<td></td>
<td>Workers’ health generally is not good</td>
</tr>
<tr>
<td>Possibility of exploitation</td>
<td></td>
<td></td>
<td>Lack of Health Insurance, retirement, other benefits</td>
</tr>
<tr>
<td>Workers minimally trained</td>
<td></td>
<td></td>
<td>Possibility of being exploited</td>
</tr>
<tr>
<td>Heavy dependence on one worker</td>
<td></td>
<td></td>
<td>Transportation available is limited, problem for many</td>
</tr>
<tr>
<td>Uneveness of case management role</td>
<td></td>
<td></td>
<td>Racial disparities in job opportunities</td>
</tr>
<tr>
<td>Some have a hard time finding workers</td>
<td></td>
<td></td>
<td>No paid vacations or respite</td>
</tr>
<tr>
<td>because of location, being “difficult” persons</td>
<td></td>
<td></td>
<td>For some workers the work is isolating</td>
</tr>
</tbody>
</table>
Strengths of the Model. Participants have adamantly stressed the strengths of this model, with many explicitly comparing it to the apparent alternative, care delivered by a home health care agency or a nursing home, and the presumption that the alternative would be more rigid, prescriptive, bureaucratic, and inflexible. Most elderly disabled service users articulated appreciation for “their worker” in a most personal way. They knew why they had chosen this person, what the worker did well, and why they enjoyed seeing them regularly. Many had hired persons they knew, not because of their “qualifications” nearly so much as because they knew and trusted them. Often on some level they were also committed to helping this person by providing a job. The duties performed varied far beyond the users’ specific illnesses and disabilities. Tasks assigned encompassed the consumers’ needs as well as preferences, largely reflecting their social class. Vastly different “weights” might be assigned to Mrs. Sharp’s need for Grace to wash her windows and take her out to lunch, Mr and Mrs. Bono looking forward to their chats with Paige, and Lilly’s public housing neighbor’s inattention to her dribbling urine that necessitates continual mopping of her linoleum floors.

Family members caring for COP clients attest to the authentic choices it offers to daughters and spouses about whether and how to keep outside employment. They value the control they share with the client (usually their mother) over her care and how it is delivered, and how they may manage their own relations with workers. When they are present and wish to be, family members, who are already intimate partners in care, are included as integral decision makers in these three way care arrangements.

Only a few of the COP workers sampled here had done other health care work, but most felt that COP was better than working for an agency because it was more flexible. COP also provided more discretion to do what one felt was right, paid commensurate with the hours one worked, and facilitated workers’ long term relations with clients. For several workers with limited work histories, the work provided entry level job experience and better opportunities. For others it provided satisfying work that complemented the workers’ own family care responsibilities, other employment, and current lifestyles. Most really enjoyed their helping relationships with clients.

Limitations of this Model. Elderly disabled clients’ experiences with independent care do reveal some disadvantages for them. In most cases clients were heavily dependent on one single worker and getting backup coverage was sometimes a problem. While we saw no cases of worker exploitation or neglect of the client, over half of the clients had no family members at all to turn to for assistance. There was frequently no one else looking out for them except the DOA case manager. Clients usually do have to accommodate the worker they really want. Most workers have had little or no training; clients who “get the most” from their workers have typically had supervisory experience before. Very poor and black elders are least likely to complain about their carer, but most likely to have chosen a helper who they already know and, in fact, help in return. (Indeed, co-residence with workers was both cost-effective and effective from the client’s perspective.) White elders in middle income neighborhoods seemed to have more difficulty finding workers.

By subsidizing homecare, and allowing family members to be paid, some families became even more committed to keeping their relative at home and thus heavily dependent upon the client’s social security income and income from COP. They faced a huge loss, sometimes of the home itself, in the future when this individual died. While women freely made the choice to care, this choice had long term costs relative to their financial security.

Finally, the biggest limitations of the independent worker model appear to be ones affecting workers. The most central is their lack of fringe benefits, a provision Milwaukee County could rectify with a reasonable infusion of revenue and determination. The COP program provides workers no health insurance or access to group insurance, although over half of these workers have serious health problems. Over half, 57%, have either no health insurance or only public insurance (Medicaid, Healthy Start, Medicare, or GAMP which is not insurance at all). Secondly, there is need to cover other fringe benefits such as workers compensation, retirement, and vacation pay. It is unreasonable to expect workers to go year after year without any paid sick days or vacation. Third, this small sample suggests that there may be a racial disparity in the wages paid to black workers and the workers serving black clients. This disparity appears to reflect a wage disparity in the larger community, a market reality that homemcare wages are higher in higher-income areas more difficult to reach by public transpor-
This reflects larger, structural disparities in community opportunities set up by limited public transportation routes, selective routing, suburban sprawl, red lining in mortgage availability, and a concentration of subsidized and public housing in the central part of Milwaukee. Government programs should not exacerbate such unfairness.

Other issues for workers involve the isolation of most jobs, the concomitant lack of backup coverage for all clients and workers in case of illness, family emergency, rest, or training, and the lack of career paths for workers. These workers carry a huge, sometimes critical, responsibility for the lives of Milwaukee’s precious old people. Their ability to be helpful hinges on their “human capital,” their competence and the respect shown it by the larger community.

In sum, then, from the consumers’ and workers’ perspectives, looking at this program’s strengths, we see strong support among participants. Few clients complain about the long waiting list once they begin getting service. But none of the participants can see systematically the issues raised by a critical examination of all their experiences in terms of the equity and efficiency of this approach.

Profound inequities exist among the elderly people needing homecare assistance in Milwaukee county, but in some ways even greater inequities exist among the well intentioned and capable individuals working for them to provide care in their homes. Homecare is actually a totality of experience, an organic process or wholeness for all parties engaged in it. The urgent needs of one party dare not be attended to by abnegating the needs of the other. The Milwaukee Community Options Program may be one of the most consumer responsive homecare programs in the country. Its greatest limitation is that it does not do more to make up for the inequities felt already by the poorly paid and minimally trained workers quietly doing its most essential work. One principle we recommend is that COP work not be allowed to worsen the situation of homecare workers. They deserve to be handled with at least as much dignity and consideration as are Milwaukee’s disabled citizens.


Gray Market in Home Care for the Elderly
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Book Chapters


Papers, Posters, and Lectures Presented Nationally and Internationally


Keigher, S. (1998). Women and Home Care in One American City. Public Lecture, Queen’s University-Belfast, Northern Ireland.


Keigher, S. & Luz, C. A Qualitative Study of the Private In-Home Care Gray Market: Consumer and Worker Perspectives. Poster (Refereed) at American Society on Aging, Nashville, TN. March 24-25, 1997. Poster was also presented at Wisconsin Chapter NASW Conference, Marriott Hotel, Milwaukee, May 15-16, and at UWM DOCE Conference on Recruitment and Retention of Home Care Workers, Marriott Hotel, Milwaukee, March 1997.


Presentations to the Milwaukee Community


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