



U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy



CASE STUDIES OF SIX STATE PERSONAL ASSISTANCE SERVICE PROGRAMS FUNDED BY THE MEDICAID PERSONAL CARE OPTION

December 1991

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SITE VISIT METHODOLOGY

State Program Selection

Selection of programs was based on information gathered in the 1985 and 1989 surveys, as well as an interview conducted with Deborah Lewis-Idema, a researcher who had just completed a study of the Medicaid Personal Care Option. The states were chosen in order to represent different systems of service delivery, different provider arrangements, different sized programs, and different geographical areas. An attempt was made to avoid visiting programs which had already been studied intensively by other researchers in the field (i.e., NY, OK). The six sites chosen and the dates of the site visits were:

1. Montana Medicaid Personal Care Services Program--October 22-26, 1990; Inter-Mountain Region; Small program (736 clients in 1988); Single statewide agency provider; Switched to this provider mode from independent providers.
2. Michigan Home Help Program--November 12-16, 1990; Midwest Region; Large program (33,000 clients in 1988); Independent providers including some family members.
3. Oregon In-Home Services Program--December 3-7, 1990; Northwest Region; Medium program (2,594 clients in 1988); Agency Providers contracted by the counties; Part of an integrated service delivery system (Senior and Disabled Services Division).
4. Massachusetts Independent Living Personal Care Program--January 21-25, 1991; Northeast Region; Small program (1,518 clients in 1988); Independent providers with training, support, and billing through independent living centers.
5. Maryland Medical Assistance Personal Care Services Program--January 28-31, 1991; Eastern Seaboard Region; Medium program (4,000 clients in 1988); Independent providers bill state Medicaid office at a daily reimbursement rate.
6. Texas Primary Home Care Program--February 25-March 1, 1991; Southwest Region; large program (33,000 clients in 1988) Multiple agency providers compete for each client contract.

Location Selection

At each site, the research team attempted to spend two or more days in the state capital, meeting with state administrators, advisory groups, advocacy groups, county administrators, and local consumers and providers. An additional one to two days were

spent in another county, talking with county administrators, as well as advocates, local consumers, and providers.

Interviewees

At each site, the research team interviewed 25-50 individuals, each of whom was involved in some fashion with the Personal Care program in that state. Attempts were made to talk with one or more representatives of each of the following groups:

1. Program advisors - advisory boards (both agency and interagency), and individuals responsible for the development of specific program policy were contacted in each state.
2. Program administrators - individuals who oversee the delivery of program services to consumers at both the state and local/county level were interviewed at each site. This included state administrators, local/county administrators, supervisors, and case managers. Administrators in other state departments were sometimes contacted if they were involved in related service provision (e.g. Vocational Rehabilitation, Aging Services).
3. Program advocates - attempts were made to contact representatives of each of the following groups: (a) Consumer advocacy groups (e.g. ILCs, ARCs, UCP, Grey Panthers, other senior advocacy groups); (b) Associations/unions representing attendants (both agency and independent providers); (c) Homecare agency associations.
4. Consumers - ILCs and/or other advocacy groups convened one or more small focus groups of service recipients.
5. Providers - provider agency administrators, nurse supervisors and attendants were interviewed whenever possible.

To identify the above individuals, the research team relied primarily on the recommendations of the state program administrators, as well as WID's existing connections with independent living centers, ARC, UCP and other groups. Many states did not have organized advocacy groups involved in PAS policy, so contacting representatives of key populations (i.e. elderly people, people with head injuries, people with mental illness) was difficult or impossible. Access to consumers was often limited because of logistical difficulty in organizing and transporting people who use PAS to a single site for group interviews. In some states it was impossible to contact attendants, because of logistical constraints, notably lack of reimbursement mechanisms.

Questionnaire Design

A questionnaire was designed to address key program policy issues, including: program history, program objectives, population served, current federal regulations, the impact of proposed HCFA regulations, attendant withholding, tort liability, gatekeeping mechanisms, support services, program expenditures, and the relation of personal care to other state programs. These issues were identified based on prior WID research and on interviews with other researchers and advocates. This questionnaire was used with administrators, advisory groups, and advocates. Two other questionnaires were designed for consumers and attendants, which focused more on personal experiences with the program.

Interview Format

Both individual and group interviews were conducted by one or both researchers. Questionnaire protocols were used for each interview, but not all items from these protocols asked at each interview, rather items were chosen based on the expertise and preference of the interviewees as well as to fill gaps in the researchers' information. Interviews took from 45 minutes to 2 hours, depending on availability of interviewees.

Materials Gathered On-Site

Before each site visit, the state administration was mailed a program summary derived from 1984 and 1988 survey data and asked to verify the accuracy of the figures. State administrators were also asked to collect the following printed materials during the site visit (if available):

1. Itemized program budgets, and related financial reports from the past three fiscal or calendar years.
2. Total hours of PAS (or other unit of service) billed for the last three fiscal or calendar years, broken down by service type and/or population.
3. Any program regulations (including, but not limited to: Eligibility Requirements, Type of Services Provided, Service Limits, Supervision/Case Management Requirements, Waiting Lists, Attendant Compensation and Benefits, Family Providers, Emergency Services, Quality Assessment, and Cost Control)
4. Assessment tools and procedures, appeal protocols.
5. Published resources and training materials for consumers, families, and providers.
6. Any internal research: cost-benefit analyses, needs assessments, audits, evaluations, etc.

7. Demographic data on the population served: age, sex, ethnicity, type and severity of disabilities.

Programs varied markedly in their capacity to provide these materials, but program regulations and assessment tools were available for each site.

Reporting Procedure

Program reports were based on interviews and the materials gathered on site. Copies of these reports were mailed to state administrators and to key advocates in each state for review. All advocates and all but one of the state administrations reviewed the reports, and these comments were incorporated whenever possible into the final report. Several administrators felt that the reports were too critical, or overstated the conflict between the state and advocates. This probably unavoidable, given the methodology. Because many representatives from different groups with different agendas were interviewed, there are inevitable inconsistencies and even contradictions on some issues. Whenever there were opposing points of view, an attempt was made to identify the contradictory sources of information. These programs are part of a constantly shifting political and economic climate, and therefore subject to constant modification. The information presented here represents the programs at the time of the site visits, but may no longer be an accurate portrait of the current program structures.

MONTANA MEDICAID PERSONAL CARE SERVICES PROGRAM

Administered by: Montana Department of Social and Rehabilitation Services

Date of Site Visit: October 22 to October 26, 1990

I. Program Overview: Size and Type of Population Served, Service Delivery System, Expenditures, Program Objectives

The Medicaid Personal Care Services Program is one of two personal assistance service programs in Montana administered by the State Department of Social and Rehabilitative Services (SRS). The program had a budget of \$3,872,000 in FY1990, and served an average of 608 people per month. The program serves Medicaid eligible people (income eligibility is 74% of poverty level for single individuals and 83% of poverty level for couples) who need assistance with activities of daily living. Service is capped at 40 hours per week. Services are provided by a single statewide contract agency.

The Medicaid Personal Care program's main objective is to help people stay in their own homes as long as possible rather than rely on nursing homes. Cost containment is an explicit part of this objective. Roughly 60% of the clients are elderly, and receive an average of 14 hours per week.

II. Program History

Montana began a personal care program in 1977. Up to that time, Title XX and state funds paid for county homemakers to do personal assistance and to transport people to doctor appointments. The state did a study to examine the possibility of getting Medicaid funding to maximize federal matching funds. It was projected that the state could train county homemakers in personal care, and then charge the personal care time to Medicaid. One hundred and fourteen full time county homemakers from all over the state were trained as personal care attendants. However, the counties were unable to keep an accurate record of personal care hours, so the state was unable to get the Medicaid match.

In order to centralize billing at a state level, in 1979 the Medicaid section of the SRS started awarding personal care service contracts directly to individual providers who were recruited by disabled individuals and billing this service through the PC-Option. There was no formal outreach conducted, only a word of mouth arrangement among county social service workers who would call the state Medicaid department

when it appeared that homemaker services were not enough. Workers were paid minimum wage plus a small percentage intended to pay for withholding taxes, and county nurses provided the supervision. A single nurse in the DSRS was responsible for managing the PC-Option program, so oversight and enforcement of regulation was necessarily limited. Most of the first recipients were young disabled people, and the number of hours of service provided per individual per week could range as high as 130.

Then in 1983, a Medicaid Waiver program was started for people who were nursing home eligible. This program stressed case-management as well as PAS, and capped total service expenditures at 80% of nursing home costs (this service cap had apparently been part of the state Medicaid regulations on PAS prior to the advent of the Waiver program, but there was no systematic enforcement until this point). The program began slowly: regional case-management teams were phased in county by county. In 1984-85, the waiver program staff began an extensive outreach campaign, which included community meetings, brochures, etc. This increased the county social service systems' awareness of regular Medicaid personal care services as well as waived services: people who were not eligible for the waiver (i.e. they were not nursing home eligible), could still receive PAS.

The caseload for Medicaid Personal Care Services began to rise dramatically, and administrative pressures on the limited staff in the state office also rose. Program administrators related anecdotes of early morning phone calls from angry and frustrated consumers who's attendants had not shown up. The increasing administrative demands for this program were further aggravated by a conflict with the state Department of Labor. Several attendants who wished to file for worker's compensation brought their case to the Department of Labor, who determined that attendants could in fact be considered state employees (see section on Liability for a further discussion of this issue).

Because of the labor issues and increased administrative demands, the DSRS made an internal decision to switch to a contract agency model of service provision. An RFP was let in the fall of 1986 for regional contract agencies and concurrently for a single statewide contract agency. The RFP required that the chosen provider would have to be ready to begin service provision on Jan. 1, 1987. No bids were received for one of the regions, so West Mont, a single nonprofit homecare agency, received the statewide contract to provide PAS throughout Montana.

The implementation period was extremely short; West Mont had less than three months to develop and implement a statewide administrative system. In this implementation period, personnel policies and intake and evaluation procedures needed to be developed, and staff had to be hired, and a personnel policies. All independent providers employed in this program were required to transfer onto the West Mont payroll. In essence, this meant a cut in an already low wage, because very few of the providers were actually paying their withholding taxes (see the Attendant Issues section for a discussion of withholding).

To structure the program, West Mont relied heavily on Medicaid program regulations that had, before this point, been enforced rather sporadically. This had a dramatic impact on the services received by some clients. Some providers had been performing paramedical services, despite prohibitions in the state's Nurse Practice Act. These services were now prohibited. Relatives who had not identified themselves as such were in some cases being paid as attendants (this was particularly problematic among Native American consumers, who traditionally rely on family for such assistance), but were not allowed to become West Mont employees. Medical supervision had been inconsistent, but West Mont stressed rigorous inclusion of nurses through their agency. The new emphasis on medical supervision seemed intrusive to some clients who were used to the previous system.

Also in 1987, the program changed the rules regarding provision of services outside the home. Prior to this decision, SRS had allowed attendants to accompany recipients outside the home to school, on vacations, on shopping trips, etc. The DSRS learned of three lawsuits in other states which ruled that the Medicaid statute on personal care is limited to the home, so the state decided to change their regulations to reflect this.

These program changes were met with considerable resistance from consumers, attendants, and the Independent Living Centers. The ILCs felt that the DSRS had not planned the transition well, and failing to consult with consumers, attendants, and advocates. In response to this conflict, the state formed an advisory body of providers, consumers, case managers from the waiver program, etc., to advise West Mont and the Dept of SRS. The Personal Care Advisory Committee has no budget and no statutory mandate (which is an ongoing frustration for at least some committee members), but it has created a "buffer" between the state program and the consumer because of the consumer and ILC representation.

The change to a single statewide provider agency has had both positive and negative repercussions for consumers. Older people appear to like the change; as one administrator observed: "they do not want as much involvement in choosing an assistant, in part because they receive less intrusive services". Program services are more available, particularly in rural areas, because the contract agency is statewide. The program is generally more accountable, attendants receive training, and availability of emergency workers has increased.

Some advocates and consumers feel that the agency model changed the relationship between attendants and consumers. Instead of hiring and managing their own attendants, they are now dependent on the agency for scheduling an increasingly limited number of PAS hours from numerous and constantly changing West Mont employees. In some cases (particularly among consumers with a high level of need), there was more attendant stability when the program used independent providers. One reason for this was that the consumer recruited and hired the attendant, so there was a more personal and individually accountable relationship. Advocates say that some

consumers have experienced a decline in their quality of life because of limitations on paramedical services, limitation of PAS to the home, higher level of medical supervision, and a decline in total hours of PAS provided.

The program's caseload has continued to increase in recent years. This may reflect, in part, an increase in the number of older people with relatively less severe disabilities included in the program.

III. Gatekeeping and Supervision Functions: Eligibility, Needs Assessment, Case-Management, Medical Supervision

A. Eligibility Determination

Initial financial eligibility for Medicaid is assessed by the DSRS. Referrals can come from a number of sources (i.e. discharge planners, physicians, social workers, self, family, etc.). West Mont begins service upon verification of income eligibility, although in some cases they may initiate services for people who are not immediately income eligible but must spend down to Medicaid level. The agency technically has up to three weeks to notify the referral source of initiation of services, but in practice less time is required.

If there is a hazardous home situation or immediate risk of institutionalization, an emergency referral can be made. In these cases, the agency must contact the individual within 24 hours, and start providing services within 48 hours pending Medicaid verification.

Assessment of ADL needs is done by a West Mont nurse supervisor. At least one ADL is required for eligibility, and hands-on personal care rather than supervision must be the primary need of the applicant.

At the time of the assessment, the nurse supervisor give the referred individual a booklet which outlines the services which are and aren't covered, a list of West Mont contact personnel, and a description of the complaint procedure. There is an appeal process for denial of services, but some advocates felt that many consumers who are deemed ineligible for services realize that they can appeal.

B. Needs Assessment

A detailed plan of care is developed by the RN with the recipient, which assesses medical diagnosis, medications, diet, short and long term objectives, etc. As part of this plan of care, the type and frequency of specific ADL related tasks are listed. The client or surrogate is required to sign a consent and release form once the plan of care is adopted.

C. Case Management

Case-management is not a regular service of the Medicaid Personal Care program. People who need case-management are referred to the Waiver program. The SRS liaison, program managers, and West Mont program director are all social workers.

D. Medical Supervision

The amount and consistency of nurse supervision increased when West Mont took over the program. West Mont RNs are required to complete a plan of care every 90 days. Originally RNs were required to complete a plan of care every 60 days, but the DSRS and West Mont decided that the majority of consumers were stable and the attendants consistent enough that this level of supervision was unnecessary.

The physician must order services, and is required to reauthorize services at least once a year. Nurse supervisors attempt to contact the recipient's physician verbally prior to assessment. In some cases, instead of waiting for the physician to initiate reauthorization of services, West Mont often completes the assessment and mails the results to the recipient's physician for a signature.

IV. Service Limits

A. Total Services Allowed Per Consumer

Service is capped at 40 hours per week, although with prior approval by the DSRS, services above 40 hours can be provided for brief periods (e.g. post hospitalization). Over the years, as the cost per service unit has increased, the number of service units delivered has decreased. When independent providers were being paid \$3.85/hour, the maximum number of hours per individual allowed was 70 per week. When the West Mont contract started in 1987, the unit cost was established at \$5.25/unit, but wages (less required withholding) and maximum hours remained stable. Deciding that this pay rate was too low to retain attendants, West Mont terminated their contract with SRS on January 1, 1988. The contract went out for bid again. West Mont received a new contract in which the per unit cost was raised to \$7.45, the attendant wage was raised back to \$3.85 plus benefits, and the maximum hours per consumer were decreased to 56 hours per week. The per service rate was raised to \$7.60 on 7/89. At that time, PCA wages began to go up, first to \$4.00/hour, and then to \$4.30/hour. When wages were raised, maximum services per person dropped to 40 hours/week. At the time of each change, those receiving the higher levels of service were grandfathered in (there are a few people receiving over 100 hours/week under this clause).

It is clear that quality of life for some consumers is being adversely affected by the service limits. Moreover, nurse supervisors point out that cutting hours may not decrease overall costs. The logistical demands of coordinating attendant services

increase as the maximum hours decrease, because more attendants are needed to visit for brief amounts of time to meet minimum ADL needs of clients. This leads to increased administrative costs, which may offset some of the savings obtained by limiting billable hours.

B. Type of Services Offered

1. Paramedical Services

The state's nurse practice act prohibits the provision of "invasive medical procedures" by unlicensed individuals, and prohibits tasks like injections, internal catheters, bowel programs, etc. Although the regulation did not change when agencies took over service provision, adherence to the regulation increased markedly. Previously, IPs had apparently performed paramedical functions (i.e. injections, dressing changes). Currently, the state subcontracts with home health aides (HHAs) to provide medical services. Increasing nurse supervision and using HHAs has increased program costs.

2. Emergency and Respite Services

West Mont has on-call attendants at all times for emergencies. A recipient must have an ongoing need for services; respite by itself is not an allowed service.

3. Homemaker Services

The program doesn't allow attendants to perform heavy maintenance or chore services, e.g. chopping wood, shoveling snow. Housekeeping services are not provided except as incidental to personal care.

4. Supervision

Supervision is not a primary task allowed in the Medicaid Personal Care program (although clients who need this service may be served by the Waiver). In practice, tasks may be spread out over the day or week, as a way to monitor some consumers.

As part of the referral process, physicians are required to assess the consumer's ability to take care of their own health and safety needs for the time they are not receiving attendant services. The program therefore makes the general assumption that the individuals referred are competent to self-manage when the attendant is not in the home.

West Mont and SRS administrators expressed concerns about this policy in some individual cases, but ultimately the decision to utilize the program rests in the hands of the consumer. If the nurse supervisor thinks a recipient's health and safety needs are in jeopardy, s/he may make a referral to Adult Protective Services (APS). In the past, such individuals would probably have been denied services altogether, and most likely referred to a nursing home. Now APS assesses an individual's competence

and the risks of staying in the community with only 40 hours of service per week, and asks the individual or a guardian to decide if he or she is willing to take these risks.

C. Location of Service Provision

Provision of PAS is now limited to the consumer's home. With prior authorization, the state will provide PAS to people in foster or group homes if the individual's that are more than is normally provided for in these homes. An attendant sharing co-op facility for people with physical disabilities is currently under construction in Missoula with HUD funds, and PAS will be paid for by the Medicaid PC-Option to residents.

V. Support Services Available

A. Attendant Management

1. Attendant Recruitment

West Mont usually does this, although they actively encourage the consumer to recruit their own attendants and refer them to West Mont for hiring and training. The general impression among advocates and providers was that this did not occur very frequently. Consumer choice of attendants is therefore usually limited to the current attendant pool.

2. Attendant Screening

West Mont does an initial screening of applicants.

3. Attendant Interviewing

West Mont does all hiring procedures.

4. Attendant Certification

There is no certification required, although there was some talk of requiring attendant certification in the future.

5. Attendant Hiring

West Mont does all hiring procedures.

6. Attendant Training

An initial 16 hour training is required, but can be waived if the attendant is a certified Home Health Aide or LPN. The training includes orientation to the agency/community services, body mechanics/transfer/assisting patient mobility,

personal care skills, care of home/personal belongings, safety/accident prevention, food/nutrition/meal preparation, and health oriented record keeping, including time records. West Mont may also set up one to one training with the consumer in order to learn techniques specific to that individual. Some attendants felt that more of this type of on the job training would be useful. This training requirement is apparently in conflict with the staffing demands in some of the local offices; training occurs on a regular schedule (e.g. monthly) but turnover occurs all the time, so attendants may end up working before they receive training if the nurse supervisor considers them competent.

An additional 8 hours of in-service training are required each year. Four hours are a review of the 16 hour training, and another 4 are in topic specific modules offered throughout the year, e.g., AIDS, death and dying, diabetes, etc.

7. Attendant Supervision

The nurse supervisor is required to make sure the plan of care is being followed. According to nurse supervisors, some informal monitoring may occur among attendants, i.e., since several attendants usually serve each recipient, they can tell whether the attendant who came in before them did the tasks required.

8. Attendant Payment

Attendants are paid an hourly wage and mileage reimbursement by West Mont.

9. Attendant Termination

West Mont is responsible for attendant termination.

10. Conflict Resolution

Recipients can contact the scheduler or nurse supervisor if there is a problem, and West Mont administrators stressed their willingness to respond to consumer complaints. In practice, some advocates say the Toile of West Mont as the single source of attendant services creates a power dynamic where consumers are afraid of "rocking the boat" by complaining about their attendants. The DSRS has a formal appeal process if the recipient is unable to resolve the conflict with agency staff.

B. Consumer Support

1. Consumer Advocacy

There is no formal mechanism for consumer advocacy outside the West Mont and DSRS system, although independent living centers provide advocacy and peer support in some areas. If services are terminated, a detailed explanation is provided for the discharge which also outlines options for appeal. Services are continued throughout the appeal process.

2. Consumer Training

No consumer training is offered.

3. Consumer Outreach

West Mont does some outreach to different professional groups to inform them of the services available.

4. Quality Monitoring

There is a bi-annual state compliance review of West Mont which looks at components mandated by the program, i.e. medical supervision, assessment, training, maintaining attendant pools, billing procedures. West Mont also conducts quarterly interviews with a small subset of service recipients to assess satisfaction level.

VI. Attendant Issues: Family Providers, Wages, Benefits, Withholding

A. Family Provider Regulations

The program has used a rigid HCFA definition of family exclusions (i.e. husband, wife, parent, child, sibling, adoptive child, stepparent, stepchild, stepbrother, stepsister, father in law, mother in law, daughter in law, sister in law, brother in law, grandparents, grandchild are not allowed to become providers) since 1982, but compliance wasn't monitored before West Mont. The exclusion of all family providers apparently caused particular problems for Native American consumers, who have a strong cultural tradition of family support. Many of these consumers simply dropped off the rolls.

B. Attendant Wages

The starting hourly rate for West Mont attendants is \$4.00, which is raised to \$4.30/hour after 3 months. This wage is paid for travel to and from the recipients home, as well as time on site. The demands of a growing caseload have increased pressure on West Mont to recruit and maintain an adequate labor pool. West Mont and the DSRs, pointing to an attendant turnover rate of approximately 150%, have lobbied the legislature for increases in the per unit reimbursement by the state, in order to pay for increased attendant training, wages and benefits, as well as increased administrative costs. The reimbursement level has been increased, but in order to curtail the increasing costs of the program, services have become more limited.

The state currently pays a total of \$7.75/hour of service, 71% of which goes to attendants. Overall, West Mont Administration says that 89% goes to salaries and taxes and 11 % goes to fixed costs. The specific breakdown provided by the SDS is:

\$ 5.52	PCA Wages and Benefits (including overtime)
\$ 0.97	Administrative Staff (includes scheduling)
\$ 0.67	Rent, Supplies, Travel, etc.
\$ 0.47	Nurse Supervision for PCAs
\$ 0.12	PCA Training

\$ 7.75	Total Cost Per Hour

C. Attendant Benefits

Social security and worker's compensation are deducted, and health insurance is offered. Personal leave and overtime for holidays are also offered.

D. Withholding and Liability Issues

As can be seen from the program's history, attendant liability issues were a critical catalyst in Montana's decision to switch to an agency provider. Until 1984, attendants were paid \$3.85 an hour, \$.50 of which was supposed to go to social security, worker's compensation and unemployment insurance. In fact, most attendants did not do any withholding, and pocketed the entire \$3.85/hour. In 1984, some former attendants applied for unemployment insurance. The DSRS claimed that the attendants were independent contractors, but the Montana Department of Labor ruled that attendants were state employees eligible for worker's compensation and unemployment, and that the DSRS was responsible for withholding FICA. The DSRS appealed the decision, but ultimately paid back withholding to the DOL.

The state did not want the 1500 attendants considered as state employees, and feared that the DOL ruling would be used to lobby for provision of full government worker benefits to all attendants. To avoid this possibility as well as to be rid of withholding responsibilities, the state administration decided to shift to an agency mode as soon as possible. When a single state provider agency was selected, the majority of attendants working in the program became West Mont employees. Because West Mont began to do withholding, attendants received \$3.35/hour and the other \$.50 went for benefits. Attendants lobbied the legislature because they felt they had in fact received a pay cut. At that time, West Mont began to receive \$5.15 per hour to cover the costs of nurse supervision, administration, and an additional \$.19 needed to augment the withholding for attendants. Lobbying has continued to increase the state reimbursement rate in order to provide higher wages and benefits.

VII. Program Context: The Relation of Medicaid Personal Care to the State Service Delivery System as a Whole

A. An Overview of Other State Programs

The other source of PAS in DSRS the Medicaid Home and Community-Based Services Waiver program (which has a slightly higher budget and caseload). This program involves varying degrees of case-management and may provide services other than personal care. The Waiver program has an extensive waiting list. A Title III program offers services primarily homemaking services to older people.

In general, services for people with disabilities are fragmented among disability groups in Montana. There are departments in the state government concerned with the services for those with DD, ED or those who are aging, but adults with disabilities as a whole do not have a department which addresses their needs. There are referral relationships across departments, i.e. Social and Rehab Services, DD Council and Family Services.

B. Who is Falling Through the Cracks?

According to some advocates, people with exclusively cognitive or mental disabilities who primarily need supervision are not adequately served by either the waiver or personal care programs. Under the waiver, people who are nursing home eligible can theoretically get up to 40 hours of personal care per week as well as case management, as long as the total cost of services falls below the expenditure cap (if extensive case management or other support services are provided, less than 40 hours of attendant care are available). Homemaker services, respite services, adult day health, nursing, transportation, environmental modification and other services are also available under the waiver.

Individuals with an ongoing level of need higher than 40 hours (other than those who were grandfathered in before service caps were set) are not served by any attendant care program in the state, except for 7 slots on the Waiver program for people who otherwise would need 24 hour hospital care. When administrators were asked "what happens now to the people who come into the program needing more than 40 hours per week of services?", the answer varied with the respondent, from "there has been no increase in nursing home utilization rates so people are simply making do" to "those who can move to other states". Advocates say that such individuals are remaining in nursing homes, or attempting to link together additional community or personal resources.

C. The Political Future of the Personal Care Program

The state may soon switch to regional contract agencies rather than a single statewide contract. The contract with West Mont is coming up for renewal in June of 1991, and since there is a more reasonable implementation period, the regional

approach may be feasible. State administrators suspect that cooperation and contentment may be higher because there is a perception in the counties "that anything administered from Helena can't be any good". The program would be administered closer to home and this would make dealing with individual problems easier. However, provision in rural areas might become even more difficult, and there is some concern that administrative costs may increase markedly with a decentralized administration.

The Personal Care Advisory Committee has proposed a more consumer-directed pilot project. The pilot is intended to serve a small number of people. This is because the rationale for the pilot was based primarily on the results of a conference the advisory committee hosted in Montana with New York's Options for Independence in December of 1989. Looking at utilization rates in New York, Options for Independence concludes that only 1% of the recipients in the state are actually functioning at a high enough level to be self directing. After examining their caseloads, West Mont supervisors and DSRS administrators concur with this figure (although other national disability advocates consider this estimate extremely low).

The pilot project was almost derailed when the chair of the committee, a person with a disability who was also a member of the state legislature, proposed a case-management based program during the legislative session, claiming he had the backing of the full advisory committee. This project was dramatically different from the self-management model many members of the committee had envisioned. Not surprisingly, the legislature was dubious of the dissention within the committee, but ultimately passed two pilot projects.

There has apparently been no follow-up on the case-management based pilot program, and problems have also emerged with the self-management pilot RFP. The first time the RFP was submitted, only one proposal came in. Some advocates felt that the RFP required too much nursing supervision and control, and all parties considered the timeline unrealistic. The RFP has gone out again with some changes in timing, and has apparently met with a better response.

There is also talk of requiring attendant certification and creating some sort of career ladder among attendants in order to cope with high turnover, but fiscal pressures may preclude such action. The wage rate will be raised to a starting rate of \$4.25/hour on January 1, 1991, in order to reflect a rise in the minimum wage.

Individuals Interviewed on Site

Dept. of Social and Rehab Services:

- Nancy Ellery, Medicaid Bureau Chief
- Joyce DeCunzo, Services Director
- Jane Korin, Human Service Program Officer
- Mike Hanshew, LTC Bureau Chief
- Julia Robinson, Director of Social and Rehab Services

Vocational Rehab:

- Bob Maffit

Personal Care Advisory Council:

- Chris Bukula, Montana Advocacy Council
- Evelyn Hauskjold, Area Agency on Aging
- Barbara Larsen, Summit ILC
- Jan Miller, Council Member
- Joan Taylor, Case Management Association
- Dorinda Orell, Consumer Rep
- Lenke Puskas, Consumer Rep

West Mont Homecare Corporation:

- Maureen O'Reilly, West Mont PCA Program Director
- Myrna Moon, RN, Western Regional Coordinator
- Gwen Berry, RN, Central Regional Coordinator
- Ron Simpson, RN, Nurse Supervisor
- Karen Burland, RN, Nurse Supervisor
- Attendants at both Helena and Missoula sites

Summit Independent Living Center:

- Michael Mayer, Director
- Barbara Larsen, Support Services Coordinator, PCA Advisory Board President
- Consumer Forum, hosted at University of Montana

Montana Independent Living Project:

- Zana Smith, Director
- Consumer Forum, hosted at Montana ILP

MICHIGAN HOME HELP PROGRAM

Date of Site Visit: November 13 to November 16, 1990

Administrative Agency: Michigan Department of Social Services

I. Program Overview: Size of Population and Expenditures, Program Objectives

The Home Help Services (HHS) program is administered by the Michigan Department of Social Services (DSS). Program expenditures were \$91 million in FY 1990, and provides Personal Care to an average of 27,558 people per month at an average cost of \$275 per person per month. HHS serves SSI and Medicaid recipients. The program primarily utilizes independent providers and family members, although private agencies may be used in some cases. Expenditures are capped at \$333 per client per month, unless a special policy exception is authorized. The program objectives are:

1. Support the client in his/her own place of residence as the normal or preferred mode of independence and self-determination.
2. Encourage the development of maximum self-determination and independence possible in the individual and authorize services only to the extent necessitated by the individual's functional limitations.
3. Support available and functioning natural support systems (i.e. friends, neighbors, relatives) whenever possible.

II. Program History

A chore program was started by the DSS in 1972, which evolved into an informal family support program for older people and adults with mental retardation. A stipend of up to \$240 per month was given, primarily for family members and friends providing PAS. The program was state and Title XX funded, and there was little formal state policy.

This program grew steadily as more families became aware of the service, but during a budget crisis in 1978, the DSS circulated a proposal to eliminate payment to family providers. The ensuing uproar led to legislative hearings in which advocates and consumers, led by the Association of Retarded Citizens, convinced the state that the program services were important and cost-effective. The funding base was actually increased, and solidified state support for the program. The hearings also brought the

Independent Living Centers into the debate, and program regulations began to reflect their philosophy. The state director of DSS became a strong advocate for expansion of community based services to people with disabilities.

As awareness of program services grew, so did expenditures. Title XX funds began to dry up, and the DSS began looking into other sources of federal support. In 1980, after reviewing existing programs in other parts of the country, Michigan decided to add the Personal Care Option to its Medicaid plan.

DSS staff collaborated with the regional HCFA representative to maintain the main features of their existing program, but added a medical supervision component and formalized case management. They were able to get around the exclusion of family providers by defining family in a very narrow way (i.e. spouse or parent of a minor). A fee schedule for people who don't meet Medicaid income eligibility and chore services remained part of the HHS, but these services are funded solely by state dollars. The program remained fairly decentralized in terms of administration.

The service cap has inched toward its current level of \$333 per client per month, but this cap is, according to an adult service worker, "program driven, not needs driven." By keeping most payments at \$333, the state is not responsible for unemployment benefits. In 1984, formal exceptions to this cap were added to the state policy manual. Roughly 2000 people currently receive "expanded home help", most of whom are considered at risk of institutionalization. Some recipients receive ongoing case-management, including home visits every 2 months.

The state again faces a serious budget deficit, and the DSS is looking for ways to cut Reprogram expenditures. Hiring of new staff has been frozen for some time. They will try to separately identify the cost of chore services and cap or drop them completely. They are also pressuring the counties to increase the number of case-managed recipients, in order to bill Medicaid for a higher number of home visits to further reduce state expenditures.

III. Gatekeeping and Supervision Functions: Eligibility, Needs Assessment, Case-Management, Medical Supervision

A. Eligibility Determination

Adult service workers are responsible for eligibility determination, and eligibility is reassessed every 12 months. If someone has an income greater than 78% of the poverty level (the Michigan income eligibility level) then s/he has the option to spend down to the Medicaid income level on a month to month basis, based on a six month projection of the individual's income and disability related expenses. The state will pay the portion of PAS expenses after the spend down limit is reached, but the limit is so low that it does little to eliminate work disincentives.

Assets must be less than \$2000 for an individual or \$3000 for a couple; less home, car, household goods, and life insurance. Income and asset requirements are very strict for couples, and there are cases of people getting divorces in order to be eligible for service. Functional Impairment must also be documented, i.e. need for assistance with ADLs, housekeeping, or chore services.

B. Needs Assessment

A plan of services for each consumer is developed by the adult services worker, and reviewed every 6 months. The DSS has tried to come up with standard time allocations for each PAS task in order to assure uniformity in needs assessment among different counties, but has met stiff resistance from workers, who think that the proposed formulas do not take into account the differing needs and circumstances of consumers. Currently, each county has a different method for assessing the time allocated for different PAS tasks. If there is a dispute over the allotted hours in one county, individuals are asked to keep an actual log of time spent on PAS for a certain period in order to document the actual hours needed.

C. Case Management

Three different state agencies do case management with Medicaid funds, and all can access the HHS program for their clients. However, consumers may receive HHS through the DSS without any case-management after initial eligibility determination and needs assessment. DSS adult services workers are required to have a college degree and to participate in a state case-management training program. The DSS distinguishes a subset of HHS recipients as case-managed, and requires a home visit roughly every two months for these consumers. This service was originally designed for consumers who need a higher level of support, but is now also viewed as a way to leverage federal funding. The DSS bills Medicaid \$234 per case management visit, and in the current fiscal crisis considers this an essential source of staffing funds. They have therefore issued a directive that the counties must put at least 25% of their HHS caseload into case-management.

In Kent County, the local office has recently set the following guidelines for who gets on case management: (1) individuals who receive physical disabilities services from DSS, (2) expenditure exceptions who receive more than \$333 per month, (3) people who receive more than a certain number of hours per month, (4) all new cases, and (5) people in unstable or failing health. The move to increase case management has caused enormous pressure on service workers. Consumers who were formerly called occasionally now must be visited at home. When a case is opened for case management, the worker must prepare a detailed assessment and a detailed service plan. The paper work is much more cumbersome for such cases.

There has been an ongoing hiring freeze on service workers which has caused the cases per worker to jump in many counties. In one county, there are now 125 cases per worker. The hiring freeze also means that when a worker leaves a position, his/her

cases are given to remaining staff. This has led to greater tension among workers. With the increased pressures, service workers and advocates are concerned that client needs are being ignored for the sake of expediency. For example, HHS exceptions for services above the \$333 cap require a great deal of additional documentation and time. Workers may decide they simply don't have time to do the extra work.

The Area Agencies on Aging (AAAs) will become involved in case management if they are the point of entry for services. The AAAs use RNs for case management. If the individual is determined not to need such intensive ongoing services (i.e. are not at risk for nursing home placement) and qualifies for Medicaid, then case management responsibility is transferred to DSS.

D. Medical Supervision

The needs assessment completed by the service worker is mailed to the applicant's physician. Services may begin as soon as Adult Services determines eligibility, but a physician's certificate of need must be received within 60 days of the start of services. The authorization is good indefinitely, unless the physician specifies a time limit. A state RN reviews all case documentation annually.

IV. Service Limits

A. Total Services Allowed Per Consumer

Services are capped at \$333 per person per month. It is possible for an individual to receive "expanded home help" if the adult service worker documents the additional need through a special (and apparently time-consuming) procedure. Exceptions up to \$999 per month may be approved by the county supervisor. Requests for exceptions above this amount must be sent to the state office for approval. Some people who are ventilator users get \$2000 per month for 24 hour PAS (as opposed to \$8000/month for special nursing home reimbursement). There are roughly 1800 exceptions statewide.

B. Type of Services Offered

1. Paramedical Services

Attendants are allowed to assist with self-administered medication, but other paramedical services cannot be provided by the attendant. Home help may be coordinated with home health services, so that periodic nursing visits, physical therapy and home health aides may be provided in the home.

2. Emergency and Respite Services

Respite and emergency services are not a regular part of the home help program. This is seen as a real shortcoming by consumers and a disincentive to moving

out of congregate housing: those who live in congregate housing can ask attendants or friends to help out when an attendant doesn't show up, but those living independently have problems.

3. *Homemaker Services*

Light housekeeping are a part of the personal care services billed through Medicaid, and heavier "chore services" may be provided through state funds. Chore service funds are limited, however, and may be eliminated in the near future.

4. *Supervision*

Supervision is not a covered personal care service. In some cases, the fact that family members in the consumer's home may be paid for personal care allows the consumer to receive the necessary supervision from the relative as well.

C. Location of Service Provision

Home help can be provided in individual homes, board and care homes, and small group homes. Medicaid personal care funding is also accessed for adult foster care and homes for the aged, but this is not part of the Home Help program (see section VIIA for a further discussion of Personal Care in these settings).

V. Support Services Available

A. Attendant Management

1. *Attendant Recruitment*

There are no systematic recruitment efforts, in part because the state does not want to appear to be the employer. Counties maintain lists of independent providers, but these are often out of date and aren't a viable resource for consumers or adult service workers.

Because of flexible family regulations, almost half of the providers are relatives. According to case workers, most consumers have people they want to become attendants, so recruitment is not usually an issue. People who need the most help with recruitment are those who are new to the area and have few community connections, those who are difficult to work for, and those who need several attendants because they have high levels of need. People who live in congregate housing have an easier time retaining attendants because attendants can work for more than one person.

Recipients say that the low wages, lack of benefits, and low hours generally make work as an attendant undesirable. Some consumers recruit family members only because they can't find anyone else. In Kent county, the Independent Living Center has

written a grant to access DSS county discretionary funds to launch a provider recruiting project. Program regulations allow people to use agency providers, but \$333 per month doesn't buy much PAS from agencies.

2. Attendant Screening

Recipients are responsible for screening.

3. Attendant Interviewing

The recipient and service worker jointly interview the attendant.

4. Attendant Certification

The caseworker must certify that the attendant is capable of doing the tasks outlined in the service plan.

5. Attendant Hiring

Recipients are responsible for hiring attendants.

6. Attendant Training

Recipients are responsible for training attendants.

7. Attendant Supervision

Recipients are responsible for supervision.

8. Attendant Payment

The recipients are responsible for attendant payment and FICA withholding. This is one of the most controversial aspects of the program (see "attendant withholding", section VID, below).

9. Attendant Termination

Recipients are responsible for firing attendants, but lack of available replacements or back up makes this difficult. People who have live-in attendants may experience even more difficulty in firing attendants, because of landlord tenant law.

10. Conflict Resolution

Service workers are responsible for mediating disputes between attendants and consumers.

B. Consumer Support

1. Consumer Advocacy

There is no formal source of advocacy within the DSS other than the service workers. The Department of Rehabilitation has a client assistance program, and independent living centers and other groups may provide advocacy.

2. Consumer Training

Consumer training is not a regular Medicaid service. Consumers who are also involved with Physical Disability Services (PDS) may receive management training from Centers for Independent Living in some regions.

3. Consumer Outreach

There is no formal program of consumer outreach, although workers are asked to present information on program services to disability or service provider groups.

4. Quality Monitoring

Recipients are responsible for monitoring their own services and calling workers if there is a problem. DSS conducts occasional field reviews, and monitors documentation.

VI. Attendant Issues: Family Providers, Wages, Benefits, Withholding

A. Family Provider Regulations

Family members, other than spouse or parent of minor, are allowed to become paid providers. The exclusion of spouses is problematic, according to advocates. If an applicant is married, his/her spouse is required to provide PAS and housekeeping if physically capable, except during the spouse's work hours. Although many families benefit from flexible regulations on family providers, the low pay and lack of benefits make family providers the only viable option for many consumers. Because most recipients are from families with low incomes, the PAS stipend may become an important part of household resources, making it difficult for recipients to move out of the family home. Despite these problems, DSS representatives think that flexibility on this point is a strength of the program. A cost-cutting proposal to eliminate family providers, based on the assumption that the family would continue to provide PAS, seems unlikely to be implemented.

B. Attendant Wages

Wages usually are at or near minimum wage, but each county pays a different rate, from \$3.35 to \$6.00 per hour (the highest rates are in the suburban Detroit area). It is possible to make individual exceptions for a higher hourly rate, which is important for individuals needing very reliable attendants (e.g. for high level quads). A two-party check is usually issued to the consumer, who must sign it in order for the attendant to receive payment. Low wages are being challenged by a number of advocacy groups.

C. Attendant Benefits

Social security is theoretically provided for independent providers, but this depends on the recipients doing the withholding. Unemployment should be provided for attendants working for consumers with exceptions over the \$333 limit.

D. Withholding and Liability Issues

FICA withholding policy is probably the weakest feature of the program. In order to avoid responsibility for withholding (and the concomitant expenditures), the state has gone to great lengths to demonstrate that they are not the attendant employer. No workers compensation is provided to attendants, and claims brought against the state have been settled out of court. By federal law, all employees are required to have FICA withheld. For employees earning over \$333 per month, federal and state unemployment insurance must also be withheld. The current service cap is therefore driven more by administrative expediency than consumer need.

The attendant is considered an employee of the client. The employer (the client) is supposed to pay half of the FICA, the attendant is supposed to pay the other half. Not surprisingly, in some situations these minimum wage workers don't pay these taxes and instead keep the entire amount. The state adds the employer share of the FICA to the reimbursement check, but some consumers sign the entire amount over to the attendant, rather than keep track of the withholding. It takes a diligent and informed recipient to actually apply for an employer number, cash the check, deduct both the recipient and employer share of FICA, bank it and pay the IRS every quarter.

The employment tax withholding system is not automated, and the state does not furnish the IRS with copies of the attendant list. Some of the adult service workers interviewed admitted telling their clients "don't worry about withholding", on the assumption that the IRS will rarely go after such small sums of money. However, if the IRS does become aware of an attendant's employment, either through a workers compensation claim or social security claim, they may send a letter ordering the recipient to pay back taxes. The counties deal with such cases individually, and may pay back taxes if required.

The DSS recognizes that this solution is untenable in the long term, and has recommended changes. The system in general fails to provide even the most basic

protection to attendants, and this is a major barrier to hiring and retaining quality attendants. The DSS recommends developing an automated withholding system with payment directly to IRS, but the projected cost (\$3 million) precludes implementation in the near future. Advocates say, at the very least, consumers should be offered training on withholding procedures.

VII. Program Context: The Relation of Medicaid Personal Care to the State Service Delivery System as a Whole

A. An Overview of Other State Programs

The Home Help Services program is clearly the largest source of PAS in Michigan. In addition, Personal Care funds are used by the Department of Mental Health (DMH) to serve roughly 17,000 people in adult foster care, board and care homes, and supported living homes. The DMH also administers a special waiver for roughly 150 people with developmental disabilities which provides supervision, and two small waivers for children with disabilities. The DMH also offers a Family Support Subsidy which is a cash grant to families with severely disabled children which may be used for PAS.

The DSS administers a small program called Physical Disability Services to fill service gaps. Training, home and vehicle modification, transportation, physical, occupational or speech therapy may all be provided through this program. Each county receives a small amount of state money which it may use for any of these services. Service workers say that these funds are very limited, and usually run out well before the end of the fiscal year.

The Office on Service to the Aging (OSA) administers the In-Home Services program for people over 60 years old. There are no unduplicated counts of PAS recipients served, but PAS expenditures were roughly \$6.2 million in 1987 for an estimated 30,000 people. There is an extensive waiting list for these services (over 1500 people in 1987). Services are coordinated through the local Area Agencies on Aging (AAAs), and attendant services are purchased from home health agencies. The OSA has started a pre-admission screening program, which currently serves 1500 people. It targets the "frail elderly" at risk of institutionalization or already in nursing homes, and provides intensive case-management and a full range of support services as well as agency attendants. Most recipients don't have informal supports available, and half live alone. OSA administrators believe that this program needs to be expanded, because the high- need elderly population is not being adequately served by the relatively unskilled independent providers used by DSS.

Michigan Rehabilitation Services (MRS) administers two small programs which include PAS for specific populations. One is a joint project with the DSS which targets people with traumatic brain injuries and other severe disabilities, and provides intensive rehabilitation and case management as well as home help. A small pilot program at

MRS offers up to \$750 per month for PAS for people who work at least 20 hours per week. Independent Living Centers in Ann Arbor and Grand Rapids are coordinating services for approximately 20 recipients. The State Independent Living Council (SILC) is frustrated with the current expenditure level for this program, and thinks that a concerted effort must be made to address the needs of working people who need PAS.

B. Who is Falling Through the Cracks?

Despite the scope of Home Help Services, many groups of people who could benefit from PAS are unserved or underserved. The major groups who fall through the cracks are:

1. The "frail elderly" and other people who need more intensive support services or skilled services.
2. Those who don't meet income and asset eligibility. Strict requirements exclude the middle class, despite spend down formulas.
3. People who want to work. The pilot program offered by MRS could be expanded to meet the needs of this population.
4. People who are married. Strict income requirements often exclude couples altogether. For HHS recipients, the spouse is required to provide most of the service, despite the strain on the consumer, the spouse, and the relationship.
5. People with cognitive disabilities. They may end up in more restrictive settings in the Community Mental Health system, although they could live independently with adequate support.
6. People who need ongoing medical care, e.g. daily injections.
7. People who need only supervision, e.g., people with Alzheimers.
8. People who are intimidated or reluctant to enter the "welfare system". Advocates say that older people may not be accessing the service, either because of a perceived stigma or because the procedures may be overwhelming.

C. The Political Future of the Personal Care Program

A severe budget crisis, combined with the advent of a new fiscally conservative Republican administration, make program cuts appear inevitable. The DSS has been directed to present ways of reducing costs by 10% in FY 1992. Likely targets are programs funded solely by state dollars. Recipients who only receive chore services may be dropped completely, as may the "income eligibles" who spend down to Medicaid eligibility. The PDS program mentioned above may not survive the budget cuts because it is totally state funded.

The DSS has directed the counties to increase the number of case-managed recipients to 25% of the total HHS caseload, in order to bill Medicaid for a higher number of home visits. Hiring of new service workers has been frozen for some time, and this will probably continue. The added stress on county offices may negatively impact day to day delivery of services.

Elimination of family providers has also been proposed, but administrators anticipate a considerable political backlash if this tactic is used. Elimination of all exceptions has been discussed, but this would simply force many individuals into institutions and defeat the whole purpose of the program. Spend-down formulas could be restricted or eliminated.

Budget crises are nothing new to Michigan, and state administrators remain fairly sanguine despite the current climate. Long term plans exist to address the attendant withholding problem through implementation of a statewide withholding system. Discussions of increases in attendant wages are occurring. The spend down formulas are being modified to make them a more viable consumer option.

New grassroots political pressure for program expansion and change is coming from a coalition of groups led by United Cerebral Palsy (UCP). The State Independent Living Council (SILC) has a personal care subcommittee which is also working on these issues. In the past, the DSS has successfully worked with such groups to impress upon the legislature the value of the state's disability services.

POSTSCRIPT -- After the site visit to Michigan was conducted, the state instituted a series of budget cuts which directly impact the Home Help Program. Chore services were cut completely for all recipients, and those recipients who spend down to income eligibility were dropped from the program. These cuts reduced the program caseload by 400-500 people. Medicaid income eligibility was restricted, cutting an additional 1500 people from the program caseload.

Individuals Interviewed on Site

Department of Social Services:

- Ralph Young, Director of Policy, Planning and Coordination, Bureau of Employment and Adult Services
- Ron Eggleston, Manager, Long Term Care Policy Section, Bureau of Program Policy, Medical Services Administration
- DeLois Whitaker Caldwell, Director of Family Services Administration
- Jim Nye, Director of Shiawassee County DSS
- Jan Basyler, Adult Services Worker, Ingham Co. DSS
- Larry Lensing, Adult Services Worker, Ingham Co. DSS
- Vicki Pickle, Adult Services Worker, Kent Co. DSS

- Nancy Loehring, Adult Services Worker, Kent Co. DSS
- Nelson Sonderfan, Adult Services Supervisor, Kent Co. DSS

Office on Aging:

- John Peterson, Director
- Mary James, OSA staff
- Marian Owen, director of Ingham County Pre-Admission Screening Pilot

United Cerebral Palsy:

- Terry Hunt, Executive Director
- Midge Merritt, Director for Programs and Services
- Marsha More, Project Coordinator

Association of Retarded Citizens:

- Marjorie Mitchell, Executive Director

Protection and Advocacy:

- Kathy Peterson, Executive Assistant

Developmental Disabilities Council:

- Beth Ferguson, Executive Director

Department of Rehabilitation Services:

- Ted Haworth, Program Specialist
- Pam Monahan, Program Specialist

State Independent Living Council:

- Al Swain, Center for Handicapper Affairs
- Dennis Conroy, Center for Handicapper Affairs
- Joyce Chin, Great Lakes Center for Independent Living
- Kris Tomaszewski, Oakland/Macomb CIL
- Mary Lee Baranski, PAS Committee
- Nancy Jachim, Oakland/Macomb CIL
- Katrina Gentile, Oakland Macomb CIL
- Verna Spayth, Ann Arbor CIL

Kent County Center for Independent Living:

- Beth Harvey
- Tom Leonard

Program Consumers:

- Laurie Thomas
- George Burch
- Lynette Lawrence Moore
- Eugene Hitchcock
- Dan Bloomer

OREGON PERSONAL CARE SERVICES

Date of Site Visit: December 3 to December 6, 1990

Administrative Agency: Oregon Office of Medical Assistance Programs, Department of Human Resources

I. Program Overview: Size of Population and Expenditures, Program Objectives

Personal Care Services (PCS) in Oregon is a small part of a comprehensive and integrated state system of community-based services. Administration of PCS has recently been transferred from the Senior and Disabled Services Division (SDSD) of the Department of Human Resources (DHR) to the Office of Medical Assistance Programs (OMAP), as part of a larger restructuring of services. PCS is provided by certified nursing assistants (CNAs) to people with ,relatively low hour needs who meet SSI income eligibility requirements (\$5160 per year for individuals). Roughly 300 SDSD clients are currently being served through this program. The funds are also beginning to be used by the Children's Services Division (CSD) to supplement foster care for children with disabilities. Currently 120 children are being served through this program, and OMAP is planning to expand this component of PCS. Personal care is also being discussed as a source of PAS for people with mental retardation and mental illness. The objective of the PCS segment of the state's community-based services is to fill the gaps in Oregon's system.

II. Program History

Oregon began to address the problem of increasing nursing home enrollment in 1975 with a state funded program called Oregon Project Independence (OPI). Prior to this time, limited chore services were available only to people whose incomes were below poverty level, and people who could not access these services ended up in costly nursing homes or state-funded institutions. OPI provided PAS on a sliding fee scale through homecare agencies to people over 60. The program was administered through the local Area Agencies on Aging (AAAs). In 1977, soon after OPI was implemented, the Personal Care Option was added to the state Medicaid plan in order to access federal funding and provide similar services to people of all ages who met income eligibility requirements. This program was administered through the county social service offices. The state also began pre-admission screening, and expanded adult foster care and other community based residential care as an alternative to nursing home placement.

The AAAs and their advisory committees were a natural constituency for expanding and developing senior services, and they became the core of a politically powerful and organized advocacy group by the late 70s. They were instrumental in the passage of nursing home reform and elder abuse laws. These advocates began to address the duplication of effort and lack of coordination among community-based services for seniors, i.e., AAA services (OPI, senior centers, daycare, nutritional programs) and traditional 'welfare' services (Medicaid, personal care, Title XX chore service, adult foster care). The Commission on Aging formally organized the Governor's Commission on Senior Services, comprised of advocates, consumers, administrators and providers, to address these issues.

In the same period, the federal government was also growing concerned with increasing Medicaid expenditures, and was looking at new ways of increasing community based services in order to slow the number of people entering nursing homes. The Administration on Aging and HCFA developed demonstration Long Term Care Development Grants, which freed up institutional funds for community based services. They also created small Flexible Integration Grants (FIG), which provided funds to facilitate the transition to more coordinated service delivery systems. Oregon, which was already addressing these concerns at a state level, was a logical recipient of these funds.

A demonstration project was started in three counties; one county redirected funding using the LTC Development Grant, one county which made structural changes in the administrative system with a FIG, and one county restructured both administration and funding. The combination of integrating administration and targeting expenditures was very successful.

These results encouraged the Governor's Commission to develop legislation which in 1981 integrated the administration of senior services by creating the Senior Service Division of the Department of Human Resources. With this integration underway, the state successfully applied for the first of the new Medicaid Home and Community Based Waivers, a statewide extension of the LTC Development Grants created by the Omnibus Budget Reconciliation Act of 1981.

The new legislation called for a single entry point for all senior and disabled services. The agencies considered most appropriate for this function were the AAAs, but this meant integrating the informal AAA structures with the county welfare system. Most AAAs (90%) agreed to the transition, and in the remainder of the counties district offices were created for Senior Services.

This transition, from the passage of legislation to the creation of a single state agency with offices throughout the state, took place in less than a year. Friction between the major players were therefore inevitable. The state utilized a process called Negotiated Investment Strategy (NIS) within the Governor's Commission to address these concerns. Groups of five people were formed into four "tables" which represented each of the following groups: Senior Services, AAAs, service providers, elderly

advocates, and disability advocates. These groups met regularly in full day forums to clarify the roles each group would play in the new system. This process facilitated consensus and clarified policy directions. The Commission continues to meet at least twice a year, and has remained an integral part of the planning, policy, and 36 budgetary process of the state.

In 1985, the Commission helped pass the Nurse Delegation Act, legislation which modified the state's Nurse Practice Act and allowed nurses to train and supervise providers in delivering many paramedical services. This legislation has not impacted the independent providers who provide the bulk of PAS under the waivers, but has allowed for more cost-effective provision of PAS in Adult Foster Homes and other residential programs.

With the implementation of the 1915C Waiver in 1981, the PCS program's caseload dropped to its current level of 300 people. The Waiver was viewed as a more flexible program, which allowed for independent providers as well as contract providers, and set income eligibility at 300% of SSI (rather than 100% for Personal Care). Senior Services has viewed Medicaid Personal Care as a funding fall-back option. If the state didn't have to reapply annually for the 1915C Waiver, Senior Services administrators said they would have phased out PCS altogether.

A special Medicaid 1915D Waiver for people over 65 was implemented in 1987. This has stabilized Oregon's funding: the Federal government apparently cannot deny a 1915D waiver application as it can for the 1915C waiver. The 1915D Waiver does not have the "cold bed" linkage of most waivers, which tie funding to utilization of existing nursing home slots. Funding is instead based on a formula which uses the state's 1976 expenditures for nursing homes as the base level, and then adds a yearly growth factor based upon the consumer price index and an estimate of the growth in the aging population (this generally amounts to 10.5% per year).

In 1988, PCS began to use certified nursing assistants (CNAs) from contract agencies exclusively. PCS has recently (February, 1990) been transferred to the Office on Medical Assistance (OMAP), a separate entity which may serve all divisions of DHR. It is hoped that this transfer will expand PCS in order to develop services for populations currently underserved in Oregon (i.e., children, MR, MI). PCS is already being used to supplement foster care for disabled children in the Children's Service Division (CSD) of DHR, and the use of these funds for children's services will probably increase.

Younger consumers and disability advocates had expressed concern that they had been marginalized by the state's primary focus on elderly people in the development of a long term care system. This was acknowledged in 1989, when the division was renamed Senior and Disabled Services (SDSD). Another table was added to the Governor's Commission representing younger consumers and disability advocates. A more substantive restructuring was begun in the fall of 1990. The "adult transfer" creates a single entry point for younger people with disabilities who prior to this point went to the AAAs and the local welfare offices. The AAAs will now serve people

over 60, and Disability Service Offices will serve people under 60. People with disabilities who were receiving social services such as food stamps and cash benefits from the Division of Adult and Family Services (AFS) are being transferred to the Disability Service Offices of SDSD.

This transition was occurring at the time of the site visit, and the state faces some of the same issues in creating Disability Services Offices that they did in creating Senior Services Offices. The roles and expectations of the AAAs, the Adult and Family Services, and the new Disability Service Offices are still being defined. There are logistical problems and philosophical conflicts inherent in the restructuring process, and these have disrupted SDSD services. Nursing home placements have gone up in the past few months, and this is being attributed to new clients being "lost in the shuffle." The SDS is also discovering that 27% of their new clients are eligible for other community-based services, and are bracing for a jump in their caseloads for these services.

III. Gatekeeping and Supervision Functions: Eligibility, Needs Assessment, Case-Management, Medical Supervision

A. Eligibility Determination

Eligibility may be determined by either the AAAs or Disability Service offices. SDSD administrators say there is a general policy of assessing the total needs of the person, and then piecing together an individual package of services which addresses those needs. A single instrument is used, the Client Assessment and Planning System (CAPS). Income, assets, living situation, medical history, current support system, and functional limitations are all assessed. Special financial workers are responsible for determining financial eligibility and fee scales for benefits. If the applicant meets income eligibility requirements (<100% of SSI), needs assistance with at least one ADL, lives at home, and is determined to need low or intermittent amounts of skilled PAS, PCS will be offered.

The CSD caseworkers offering PCS reimbursement to foster parents do not use this system, but rather complete a special rate/personal care service authorization to add to the foster care agreement. An RN does a detailed assessment of medical and functional needs.

B. Needs Assessment

Based on the CAPS assessment SDSD clients are ranked in terms of severity of need, and services are allocated based on this ranking. People at the bottom of the list currently receiving services may be bumped if higher need cases are added. For CSD clients, the RN assessment results in a detailed plan of care which specifies the child's needs and the hours allocated to deal with those needs.

C. Case Management

Case management is offered through the SDSD and CSD offices. Case managers are civil servants, and must have a Bachelor's degree in the behavioral sciences. SDSD caseworkers have average caseloads of roughly 120 people, and are required to do in home visits every 6 months. Agency RNs may assume some case-management functions for PCS recipients. Some private agency administrators and advocates expressed concern that there is an over reliance on state workers in the current system, that some caseworkers are poorly trained, and that caseworkers are underpaid and overworked.

D. Medical Supervision

RN supervision is required every 60 to 180 days for PCS provided through SDSD, and at least every 180 days for CSD clients. The consumer's physician must reauthorize services annually.

IV. Service Limits

A. Total Services Allowed Per Consumer

Personal care is rarely provided on a daily basis for SDSD clients. Most PCS consumers receive 4 to 7 hours of PAS per week. People with extensive needs will be placed into either the waiver programs or some sort of residential program.

The CSD has set maximum monthly hours for different types of services, i.e., 100 hours/month for ADL tasks, 100 hours/month for supervision, 15 hours/month for night-time care, 100 hours for delegation of nursing procedures, etc.

B. Type of Services Offered

1. Paramedical Services

Because of the Nurse Delegation Act and because CNAs are used to provide PCS with RN supervision, many paramedical services can be provided (including external Catheter and colostomy care, medications, and respiration). More skilled or invasive procedures are provided by home health aides. Service limits preclude daily provision of such tasks under PCS.

Extensive paramedical services are offered through CSD. Up to 100 hours of "delegation of nursing procedures" per month may be authorized by CSD caseworkers. The Oregon State Health Division has developed two Pediatric Nursing Procedure manuals, which detail the provision of the 30 clinical procedures which can be delegated.

2. Emergency and Respite Services

Because hours are so limited, PCS is not a viable source of respite services for SDSD clients. There is an emergency authorization process, so PCS may be used in emergencies by SDSD.

Emergency and respite services are not explicitly listed as reimbursable personal care by CSD, but "standby assistance/intensive behavioral supervision" could be made available for emergency or respite needs of children.

3. Homemaker Services

Basic housekeeping tasks necessary for consumer health and safety can be provided by PCS. In practice, personal care is too costly to provide ongoing housekeeping services. PCS can be supplemented by waiver funds, so independent providers can be used for housekeeping.

CSD reimburses for "household assistance essential to the child's health and comfort", which may cover some homemaker services.

4. Supervision

Supervision, specifically "care of confused, mentally or physically disabled clients" is defined as a personal care service by SDSD. Because PCS is generally not offered daily, it is not sufficient for people with higher supervision needs.

Up to 100 hours per month of "behavior management and supervision" as well as up to 15 hours of "intensive behavioral supervision" may be authorized by CSD caseworkers.

C. Location of Service Provision

PCS funding is not used by SDSD for adult foster care and other residential programs. PCS is limited to individual homes, and assistance "to and from necessary appointments."

For CSD, personal care is used for foster care placement of disabled children. Provision of services is not necessarily limited to the home: supportive services such as "travel and shopping to meet the child's health care, nutritional, educational, and recreational needs" are covered.

V. Support Services Available for SDSD Consumers (CSD Data Not Available)

A. Attendant Management

1. Attendant Recruitment

Recruitment is done by contract agencies. Agencies say the low state reimbursement makes recruitment difficult.

2. Attendant Screening

Screening is done by contract agencies.

3. Attendant Interviewing

Interviewing is done by contract agencies.

4. Attendant Certification

Attendants for PCS must be certified nursing assistants.

5. Attendant Hiring

Hiring is done by contract agencies.

6. Attendant Training

The state offers a 120 hour CNA training program.

7. Attendant Supervision

Contract agency RNs are responsible for attendant supervision.

8. Attendant Payment

Attendant payment is done by contract agencies.

9. Attendant Termination

Attendant termination is done by contract agencies.

10. Conflict Resolution

SDSD caseworkers as well as agency RNs may be called in to address conflicts between attendants and consumers.

B. Consumer Support

1. Consumer Advocacy

SDSD considers its caseworkers to be consumer advocates. The Oregon Disabilities Commission (ODC), a consumer controlled (by law, at least half of the commissioners must have a disability) agency reporting directly to the governor, runs a toll free hotline for consumer complaints. Independent living centers and other disability organizations may provide consumer advocacy in some cases.

2. Consumer Training

Some SDSD/Voc. Rehab. consumers may receive training through independent living centers, but this is not a regular component of PCS.

3. Consumer Outreach

The centralization of services currently taking place through the adult transfer is also performing an outreach function. New people are being informed of in-home services, including PCS, for which they may be eligible.

4. Quality Monitoring

Periodic on-site monitoring is conducted by SDSD. SDSD also does a client satisfaction survey. The ODC also follows up on complaints that come through their hotline.

VI. Attendant Issues: Family Providers, Wages, Benefits, Withholding

A. Family Provider Regulations

SDSD clients who wish to use family providers would be transferred from PCS to the waiver programs. SDSD generally does not allow the spouse or parent of minor to be designated as a provider, although new legislation now allows for spousal pay in some circumstances paid for by the state general fund.

CSD allows reimbursement of foster parents, but natural and adoptive parents, step parents, siblings, step-siblings, and grandparents cannot receive PCS reimbursement for PAS provision. A separate state-funded program apparently does reimburse some family providers.

B. Attendant Wages

Wages for PCS attendants used by SDSD vary between private agencies, but they receive an average of \$6-7 per hour. Foster parents in the CSD program receive approximately \$5 per hour for providing personal care.

C. Attendant Benefits

Private agencies under contract with SDSD offer FICA, worker's compensation, and unemployment compensation for their CNAs. No benefits are offered by CSD to foster parents through PCS.

D. Withholding and Liability Issues

Oregon has a high worker's compensation rate, which has impacted the overall employment cost for PCS. Private agency administrators complain that the SDSD reimbursement rate is too low to offer additional benefits, and consequently they have difficulty recruiting and retaining qualified attendants. Employer based health insurance will be mandated in 1994. Private agencies have insurance for negligence.

VII. Program Context: The Relation of Medicaid Personal Care to the State Service Delivery System as a Whole

A. An Overview of Other State Programs

SDSD is committed to phasing out SNF and ICF placement whenever possible, and has created a community based system which offers alternatives to nursing homes. There is a statewide preadmission screening program. The state also provides a number of Services which are broadly characterized in SDSD literature as "in home services" and "substitute homes".

In-home services include home health, home delivered meals, special diets, home care, and Oregon Project Independence, as well as PCS. Home health, home delivered meals and special diets are self-explanatory.

Home care is defined as assistance with ADLs and "self-management activities" by client- employed or agency providers. Home care is funded by the 1915C and 1915D waivers, and makes up the great majority (over 90%) of PAS offered by the state. The 1915C waiver funds consumers under 65. It is a "cold bed" waiver, which links nursing home placements with community-based expenditures, and because of this linkage, funding is very limited for people under 65. The 1915C waiver must be reapplied for annually, but the 1915D waiver does not. The 1915D Waiver funds are based on a formula which uses the state's 1976 expenditures for nursing homes as the base level, and then adds a yearly growth factor based upon the consumer price index and an estimate of the growth in the aging population (roughly 10.5% growth per year). The

1915D waiver has the advantage of growing at a predictable rate and therefore facilitates state planning, but when expenditures jump unexpectedly (as is presently happening under the adult transfer), the state must scramble to bring expenditures down to the specified growth rate.

Home care consumers are steered into the client-employed model because of the lower cost to the state, but agencies may be used (particularly in emergencies). Recipients say lack of support services and high turnover make client employment a tenuous and time consuming process. Income eligibility is set at 300% of SSI for these services (approximately \$15,480 per year for individuals).

OPI provides PAS to people who do not meet Medicaid income eligibility requirements. This is a solely state-funded program which uses agency providers. There is an extensive waiting list for these services. Although a range of PAS and related services can be authorized, in practice funds are so restricted that services are limited to a few hours of housekeeping or assistance with low-frequency ADLs (i.e. bathing). Very few OPI recipients receive daily services.

Substitute homes include adult foster homes, residential care facilities, and assisted living facilities. Adult foster homes serve up to five people in licensed homes that function as small board and care facilities. Oregon has the highest number of adult foster care placements in the country (roughly 2500 people). Residential care facilities are more traditional board and care settings, serving six or more people. Assisted living facilities are individual living spaces which provide access to custodial care. There are currently 6 assisted living homes in Oregon, with another opening this year. PAS and skilled nursing are available on site. They differ from traditional ICF nursing homes in that they emphasize private living space and maximize consumer control in utilization of services. Staffing requirements are flexible, allowing for smaller staffs and less medical emphasis. These are a cost-effective alternative to nursing homes which allow residents to "age in place" instead of moving people to increasingly restrictive settings as their health declines.

Cost-effectiveness is a driving concern in SDSD, due in part to the strict fiscal requirements of the waivers. Consumers and advocates are concerned that this emphasis distorts service provision, as the fiscal needs of the state supersede the functional needs of the consumer.

B. Who is falling Through the Cracks?

Although Oregon has an extensive system of community based services, many services are geared primarily to low income elderly people, and other groups may be underserved or even unserved in this system. These include:

People with cognitive disabilities. The state historically has relied on large institutional facilities for people with developmental disabilities, and is now struggling to

develop community alternatives. Groups such as the Association of Retarded Citizens (ARC) are advocating a greater scope of independent living services.

People with extensive PAS needs (e.g. ventilator dependent adults) cannot really be served in their own homes unless they have access to family or other volunteer services. Live-in attendants receive less than \$1000 per month plus FICA and unemployment.

People who want to work. There are enormous, disincentives to employment because of strict income requirements for PCS and homecare. People who receive significant assistance from Voc. Rehab. to become "work ready" are unable to make the transition to employment if they have extensive and costly PAS needs. One homecare recipient interviewed had completed law school, but estimated that he would have to have a starting salary of over \$30,000 in order to maintain his living expenses and purchase PAS on the private market.

People who want to be married. SSI income eligibility for couples is very low, so loss of benefits may discourage people from marrying. The state recently passed legislation to allow spouses to become paid attendants in some circumstances through state financing.

Younger people with disabilities in general have not had their needs adequately met by the current system, but it is too early to tell whether the adult transfer will remedy the situation. In the words of one advocate, "the disabled are where the elderly were 10 years ago."

C. The Political Future of the Personal Care Program

Personal care will probably remain a small part of SDSD services unless the waiver funding is disrupted. The transfer of PCS to OMAP may dramatically increase usage of these funds to populations currently excluded from community based PAS. Although CSD is the first division other than SDSD to access these funds, divisions which serve people with mental retardation and mental illness are also examining ways to use PCS.

In general, Oregon appears philosophically committed to developing a comprehensive and inclusive service delivery system. The adult transfer currently taking place within SDSD is part of a larger process to establish parity among seniors and other people with disabilities. There is a remarkable amount of collaboration between advocates and the DHR administration, facilitated by the Oregon Disabilities Commission. The Governor's Task Force on Disability Services has recently set out a progressive reform agenda, but the measures outlined will probably be constrained by financial concerns.

Individuals Interviewed

Department of Human Resources

Division of Senior and Disabled Services:

- Dick Ladd, Chief Administrator
- Douglas Stone, Program Assistance
- Loren Simonds, Program Assistance
- Susan Dietsche, Program Assistance
- Cindy Hannum, Program Assistance
- Dexter Henderson, Contract and Provider Relations Unit
- Lance King, Unit Supervisor, Disability Services Office
- Elise Lunas, Program Manager, AAA Office

Office of Medical Assistance Programs:

- Bob Labbe, Medicaid Coordinator
- Joy Jaeger, RN

Oregon Disabilities Commission:

- Eugene Organ, Executive Director

Service Providers:

- Jo Seidl, AHM Helping Hands
- Cindy Jenkimen, UNA Health Services
- Sharon Ogren, Kimberly Quality Care
- Edie Hoerer, Kimberly Quality Care

SDSD Consumers:

- Butch Pribbanew, JD
- Dan Robinson, JD
- Dennis Scharf
- Anne Williamson
- Elsie Hastings
- Rose Reding

Access Oregon:

- Patty Arndt, Executive Director
- Grady Landrum, Service Specialist

United Cerebral Palsy:

- David Ingersol, Client Advocacy Specialist

MASSACHUSETTS PERSONAL CARE ASSISTANCE PROGRAM

Administrative Agency: Massachusetts Department of Public Welfare

Date of Site Visit: January 21 to January 25, 1991

I. Program Overview: Size of Population and Expenditures, Program Objectives

Personal Care Assistance (PCA) is administered by the Massachusetts Department of Public Welfare (DPW). It served 1,775 people in 1990, at a total cost of \$24,531,262. The program utilizes independent providers, and services are coordinated through nine PCA agencies, six of which are independent living centers (ILCs). There is an emphasis on consumer control and consumer training. Recipients meet income eligibility through either regular income limits or through the state's Medicaid buy-in, and require at least 10 hours of ADL assistance per week, or 14 hours of ADL and IADL assistance.

The program goal is "to enable people with permanent or chronic disabilities to live in the community who might otherwise be institutionalized." The program serves primarily younger people (over 90% of consumers are under 65) with physical disabilities who are capable of self management. There is an explicit commitment to consumer control, and program recipients expressed high levels of satisfaction with program services. Changes in program guidelines promulgated in 1988 allowed PCA services under the management of a consumer designated surrogate for people with mental retardation, but this population makes up only a small percentage of PCA recipients.

II. Program History

In the early 70s, Title XX funded homemaker services were provided through the Executive Office of Elder Affairs and through the Department of Social Service. Administrators in the Massachusetts Rehabilitation Commission (MRC), who were strongly influenced by the early independent living movement, began to develop transitional living programs incorporating the consumer control philosophy of independent living. They gradually moved from housing and traditional rehabilitative services to independent living and peer support. The Boston Center for Independent Living (BCIL) developed out of one of these transitional living programs. Nine other independent living centers were subsequently developed, one from a transitional living program and others which started as advocacy and peer support centers.

In 1976, the MRC had recognized the need for PAS so that people could move into their own homes and apartments, and negotiated with the state Medicaid office to access funds for PAS. Massachusetts added personal care to the state Medicaid plan, but because PCA was such a small part of the budget and the MRC was already involved, the state Medicaid office did little in the way of oversight. This hands-off approach to the program by the state Department of Public Welfare (DPW) has continued, although the state now faces federal pressure to change this relationship. Independent living centers were given the option of adding the PCA program to their service package, and currently six of the ten have done so.

For twelve years the PCA program had no formal regulation or oversight, only a set of guidelines which the ILCs adapted to fit their own community and organizational structure. It almost exclusively served adult wheelchair users who needed 14 or more hours of assistance with IADLs and ADLs. As the program expanded, lack of regulation led to inconsistencies in the administration and coordination of services. Concern also grew among representatives of other disability groups (notably ARC), because the services were limited to people with physical disabilities in areas served by ILCs. This led to increasing pressure on the DPW to define and expand the program.

The DPW responded by formally creating a PCA task force, composed of ILCs as well as representatives of other disability groups, (such as the DD Council, UCP, and ARC) to develop program regulations and iron out how people with mental retardation could be served by a program originally designed as an extension of a physical disabilities rehabilitation. The first regulations were promulgated by the Task Force in October, 1988.

The new regulations defined eligibility far more broadly, including children, and people whose disability did not require a wheelchair. A key issue addressed by the PCA regulations was the inclusion of people with cognitive disabilities who are not able to self-manage all aspects of PCA services. It was expected that the Department of Mental Retardation (DMR) would fund the additional support services needed, and the DPW would fund the PCA portion. The new consumers would be served through something broadly defined as "the surrogacy model", which involved people other than the consumer in PAS management. The new regulations defined the surrogate as "the consumer's legal guardian, a family member, or any other person identified in the personal care service plan to be responsible for performing certain PCA management tasks the consumer is unable to perform. These PCA management tasks may include hiring, firing, supervising and otherwise directing the PCA ... A consumer's surrogate cannot also be his PCA."

Many administrators and advocates in the ILCs had (and continue to have) both philosophical and practical objections to the surrogacy model. They expect the administrative resources required for the surrogacy model to be considerably higher than for self-managing consumers. Surrogates are seen as incompatible with the goals of the independent living movement: by including surrogates, particularly paid service

professionals such as case managers, the primary goals of self-determination and personal choice seem endangered. Moreover, some ILC administrators and advocates claim that the service provider functions threaten to overwhelm the advocacy function of the ILCs. By agreeing to include surrogates, ILCs will be even further committed to the business of service provision. Several ILCs discussed the possibility of getting out of the PCA program altogether. Responding to this possibility, the new regulations allow for designation of local nonprofit agencies as PCA program coordinators in areas where the ILCs refused to offer surrogacy.

The 1988 regulations were promulgated during "the Massachusetts miracle", a period of unprecedented economic growth that was nationally publicized in the presidential campaign of Governor Dukakis. An economic decline and a new Republican administration have dramatically changed that climate. The implementation of these regulations and addition of new PCA agencies was delayed, due in part to economic crisis, administrative intransigence, and political infighting among disability groups and among state agencies. During and after the promulgation of the 1988 regulations, some developmental disabilities (DD) advocates became increasingly frustrated with the pace at which the surrogacy model was being implemented, and in 1990 threatened the DPW with a lawsuit if concrete measures were not taken to include people who needed surrogacy.

The worsening budget crisis intruded into this already complicated process. The social service system in general, and the Medicaid budget in particular, were considered to be out of control. The DPW came under intense political pressure to cut costs. Restructuring and a general reduction of administrative personnel led to a loss of practically all administrators involved in any way with the PCA task force and the development of the 1988 regulations. Advocates say that the new administrators' lack of experience and understanding of the political and historical context of the PCA program and constituency it served have led created some friction between many advocates and the DPW administration.

The DMR was facing similar political and economic pressure, and began to cut services. This caused DD advocates to intensify their demands that the surrogacy model be implemented quickly, so that recipients losing DMR services could receive at least some support through the PCA program. Not surprisingly the DPW resisted adding a new population to its already bulging caseloads in the current fiscal climate. Fearing "the woodwork effect", the DPW estimated the potential cost of instituting the surrogacy model, and concluded that there was a possibility that the program expenditures could jump from \$25 to \$100 million. DD advocates consider the methodology for this estimate very suspect. It included the waiting list of MRC head injured population, the MR waiting list, the waiting list for other people with developmental disabilities (e.g. people turning 22 and no longer eligible for special education), and people in mental hospitals. Based on these figures, the DPW predicted they would add 2500 to 5000 new people to the PCA program at a cost of \$75-\$100 million. Consumer groups felt that this estimate was quite exaggerated, because it counted people who probably don't need PAS.

In the Spring of 1990, new DPW administrators drafted their own set of PCA program guidelines which contained costs by limiting eligibility and services. Proposals were drafted which suggested limiting eligibility to those who are eligible for SNFs, limiting eligibility to those at risk of institutionalization, instituting a 40 hour per week service cap, and narrowing the scope of reimbursable services. As word of these proposals spread, there was a swift consumer backlash. Some recipients threatened to commit suicide. An emotional public forum with consumers and DPW administrators was organized by members of the PCA task force. This meeting and other political pressures led the DPW to withdraw these proposals.

Between 1988 and January of 1990, there were 16 applications by potential "Personal Care Agencies" which would offer the surrogacy model of service provision, but none had been officially approved during this period. Two ILCs began to offer surrogate services, another started to offer surrogate services but then withdrew. The PCA task force began to review applications for new providers, and by August 1990 the committee had developed a criteria list. A number of home health agencies are considering applying to be providers, but they need to demonstrate a sensitivity to independent living and be able to meet consumer control goals. Two new personal care agencies were recently approved, but at the time of the site visit they were still waiting for reimbursement rates to be set by the state Rate Setting Commission.

The DPW has recently appointed a full time administrator of the PCA program, but the department as a whole seems to remain reluctant to facilitate any program development. DPW officials acknowledge that people with mental retardation and people with AIDS could benefit from PCA services, and plan to work with these groups to develop new PCA agencies.

The ILCs continue to be divided over the surrogacy issue. The ILCs also, face a divisive struggle over the issue of attendant withholding. A recent IRS decision makes the ILCs responsible for assuring that FICA is paid on reimbursements for independent providers. Regardless of how the situation is resolved, additional administration and paperwork will increase the ILC's role in PCA service delivery (a role to which many ILC advocates object).

III. Gatekeeping and Supervision Functions: Eligibility, Needs Assessment, Case-Management, Medical Supervision

A. Eligibility Determination

Income eligibility is determined by the DPW. People with disabilities may become eligible for PCA services through meeting regular income eligibility requirements, 102% of poverty level. A spend down option for income eligibility is also available; the difference in the recipient's monthly income and financial eligibility guidelines can be deducted from the monthly PCA reimbursement, and the consumer can pay the

difference to the PCA out of pocket. People eligible for 1619B do not pay a contribution in order to access Medicaid, but receive Medicaid services at no cost.

Two state-funded programs also offer PCA services to people who don't meet regular Medicaid income eligibility. Some working MRC clients are also receiving PCA services through the ILCs, but intake to this program has been closed. Massachusetts also offers a Medicaid buy-in (Commonhealth Extra) for people of all incomes with disabilities as part of the state's Medicaid services. There is no asset cap for Commonhealth Extra, and an individual may purchase a full or supplemental premium.

PCA agencies do an initial intake for PCA, then refer to a nurse and occupational therapist who are either PCA agency employees or independent contractors. The RN and OT conduct an in-home assessment of functional limitations. Eligible recipients must need a minimum of 10 hours of assistance with ADLs per week, or 14 hours of ADLs and IADLs per week. The consumer must also have a condition which is "permanent or chronic in nature."

The PCA prior approval coordinator at the ILC mails a copy of the functional evaluation to the consumer's physician for signing. The physician's authorization must be returned before the ELC forwards the evaluation to the prior authorization unit of DPW. Services may begin immediately after the PCA agency requests prior approval (although the DPW usually takes about three weeks to give formal approval).

B. Needs Assessment

The OT and RN allocate hours based on functional limitations using a standardized formula. Deviations from this allocation formula must be documented. Questionable hour allocations may lead to a denial of prior authorization. When the consumer is living with family, the family is responsible for provision IADLs when possible. When a consumer is living with other program recipients, PCA time for homemaking tasks must be split among all consumers in the household.

C. Case Management

Fundamentally, the PCA program trains consumers to be their own case managers. Medicaid pays for extensive consumer training by the ILCs, but there is no mandated contact between the ILCs and the consumer after training has occurred. The ILCs have resource coordinators or service coordinators paid by the MRC. The qualifications of such staff are based upon knowledge, skills, and ability not education.

In 1989, PCA services began to be used for as part of the service package for people who were hospitalized (e.g. people with AIDS). A special case management unit was developed for these high cost cases.

D. Medical Supervision

Services must be prescribed by a physician. An RN must do a home assessment at least once a year. The low level of medical supervision was singled out by HCFA as a flaw of the program, but consumers and advocates think that the present system is non-intrusive and cost-effective. Because of this criticism, the state is considering increasing RN supervision to at least twice yearly.

IV. Service Limits

A. Total Services Allowed Per Consumer

There are no explicit service limits for the PCA program, and a number of clients with severe disabilities receive 24 hour services. Some high need consumers complain that reimbursement for night attendants is unreasonably low, but advocates and administrators generally view the service allocation as adequate for the majority of consumers.

B. Type of Services Offered

1. Paramedical Services

Paramedical services are allowed through the PCA program. Consumers are trained in "personal health care maintenance" and "emergency management", as well as how to train and manage attendants. ILCs may contract with RNs for individual instruction on specific medical conditions. It is assumed that people with this level of training will be able to train and supervise their own attendants to perform the PAS tasks they require, including paramedical tasks. The inclusion of people who are not capable of self-management may complicate this and other aspects of the current service delivery system.

2. Emergency and Respite Services

There is no programmatic resource for consistent provision of emergency and respite services, although PCA regulations require that the PCA agencies maintain a current list of emergency attendants. Consumers are encouraged to recruit their own back-up attendants.

3. Homemaker Services

Housekeeping is part of the service plan of most PCA recipients. If the consumer lives with family, they are required to do all or most housekeeping whenever possible.

4. Supervision

Supervision is not a PCA service, but inclusion of the surrogacy model will extend PCA services to people with cognitive disabilities as well as physical disabilities; people who only need supervision will remain excluded from the program according to the present regulations.

The surrogacy model attempts to maximize consumer control, by making the recipient responsible for as many aspects of PCA management as is possible. Several ILCs limit services to people with a family member or significant other that could be the equivalent of a conservator. The cognitively disabled consumer and his/her surrogate are trained through the ILC, like the other consumers in the PCA program.

The inclusion of people without family networks to play the surrogate role who would need to rely on professionals (i.e., caseworkers, adult foster care workers) has only been done on a demonstration basis in a pilot run by UCP called the Options program in Tauton, Massachusetts. The Center for Humanistic Change in Western Massachusetts has also been approved to provide this surrogacy model. These surrogates would be funded by the Department of Mental Retardation (DMR).

The surrogacy concept remains controversial among some of the ILCs. Concerns involve not only the philosophical contradiction between surrogacy and the central tenants of independent living, but more programmatic administrative dilemmas:

- How does the disabled individual chose a surrogate?
- Who can and cannot be a surrogate? (Three ILCs will only allow family members or significant others of long standing to be surrogates. These restrictions led to 90% of surrogates involved being parents of technology dependent children under 18 with severe cognitive disabilities.)
- What if something happens to the surrogate? (Two ILCs require that the consumer designate a back-up surrogate.)
- How do you differentiate the role of the surrogate and the role of the consumer? What if the consumer and surrogate disagree?
- How do you differentiate between surrogate and attendant? Can a consumer fire a paid surrogate?
- Will surrogacy cases require ongoing case-management? Will the ILCs be required to provide this case management? Who would pay for the increased staffing requirements?

C. Location of Service Provision

PCA can be provided to people who live in individual homes, apartments, cluster housing and transitional living facilities. The state is considering expanding PCA services to group homes for special populations, including personal care homes for people with AIDS.

Approved services may be provided where the recipient happens to be. The time per task allocations are fairly strict, some consumers say that they don't allow for much flexibility to accommodate other needs outside the home.

V. Support Services Available

A. Attendant Management

1. Attendant Recruitment

Recipients or surrogates are responsible for recruitment after being trained by the ILCs. Some ILCs maintain a list of people interested in working as attendants.

2. Attendant Screening

The recipient or surrogate is responsible for screening.

3. Attendant Interviewing

The recipient or surrogate is responsible for inter-viewing.

4. Attendant Certification

No attendant certification is required.

5. Attendant Hiring

The recipient or surrogate is responsible for hiring.

6. Attendant Training

The recipient or surrogate is responsible for training.

7. Attendant Supervision

The recipient or surrogate is responsible for attendant supervision.

8. Attendant Payment

Recipients or surrogates submit a monthly invoice to the ILC, which issues individual reimbursement checks to consumers. The ILCs maintain extensive accounting departments which are responsible for coordinating processing of PCA billing.

9. Attendant Termination

Recipients or surrogates are responsible for attendant termination.

10. Conflict Resolution

Recipients are generally responsible for conflict resolution, although ILC staff are frequently called for advice.

B. Consumer Support

1. Consumer Advocacy

Recipients are considered their own advocates, but ILCs are clearly an advocacy resource.

2. Consumer Training

Extensive consumer training is probably the most unique feature of the PCA program. There is no individual cap or prior approval requirement for training, and the ILC can continue to work with the consumer until they consider the recipient sufficiently skilled to live independently with PCA services. Training has usually been a short term effort, but inclusion of people with cognitive disabilities will probably require longer periods of skills training.

3. Consumer Outreach

No real consumer outreach is done for PCA services, and this is considered a major shortcoming by aging and DD advocates. The PCA program has historically been limited to populations and geographic areas served by the ILCs.

4. Quality Monitoring

There is no programmatic mechanism for assessing the quality of PCA services the individual recipient receives, but consumers have been trained to recognize what satisfactory PAS is, and trained to insist on quality PAS. This seems quite effective, according to the recipients interviewed.

VI. Attendant Issues: Family Providers, Wages, Benerits, Withholding

A. Family Provider Regulations

Family members may not become providers, but could become surrogates. Family is defined as parent, spouse, child, son-in-law, or daughter-in-law.

B. Attendant Wages

Independent providers are reimbursed by the state at \$7.85 per hour, \$11.80 per hour on Thanksgiving and Christmas day. Night attendants receive a flat nightly rate plus an hourly wage for services in excess of 59 minutes. The ILCs receive \$0.24 per unit for administration. This is a fairly generous reimbursement, which allows consumers to recruit attendants and ILCs to pay for overhead and staff.

Until recently, reimbursement rates have been determined solely by the state Rate Setting Commission, which is responsive to consumers and providers. Critics charged that it was generally too responsive, citing inflated Medicaid reimbursement rates to medical professionals and durable medical equipment vendors. In 1989, the rate-setting commission was changed to an advisory body, so that the state Medicaid office could have a say in rate setting. DPW administrators say this was a necessary step in containing state expenditures. Some disability advocates expressed concern about the potential impact of this transition, but others say that reimbursement to ILCs is a relatively insignificant line-item on the Medicaid budget so they doubt that rates will be effected.

C. Attendant Benefits

No benefits are provided to independent providers.

D. Withholding and Liability Issues

Rules regarding attendant withholding have been intentionally vague, with no clear designation of responsibility, but this lack of policy has recently been called into question. ILCs have combined all PCA service invoices and billed Medicaid for a lump sum reimbursement. The ILC also sends individual invoices to a for profit computing service (UNISYS) which checks each invoice. The DPW compares the ILC claim with the UNISYS data, and the ILC must reconcile any difference. This is an extraordinarily complicated process which can involve hundreds of thousands of dollars each month, and the ILCs must maintain a separate accounting department to process the paperwork involved. There is no record of what actually happens to the reimbursement check after it is issued to the consumer.

An ILC was audited in 1990, and the IRS reviewed this billing process and decided that the PCAs could be designated as ILC employees. They threatened to hold the ILC liable for income tax, but then negotiated a settlement whereby the ILC would establish a formal process for designating responsibility for withholding.

Some PCA agencies are now issuing 1099 forms to consumers, and instructing them to tell their attendants that they are liable for paying income tax as independent contractors. This may have an impact on service delivery, which to this point was based on what one service coordinator referred to as "money under the table." There will be a net loss in pay, as taxes are paid, which could cause some attendants to drop out of the

system. The work force could further be depleted because many consumers are currently using foreign students without work visas, illegal aliens, and AFDC recipients as attendants. These attendants cannot report their income because of loss of benefits or potential deportation. One consumer interviewed has already lost a long time attendant because of new withholding requirements established.

An ILC staffer estimates that up to 25% of the current caseload will require a surrogate to handle the additional paperwork required for withholding. Despite these dire predictions, the policy change seems inevitable. The training resources of the ILCs may be used to facilitate the transition, but some disruption of services is likely.

VII. Program Context: The Relation of Medicaid Personal Care to the State Service Delivery System as a Whole

A. An Overview of Other State Programs

Services in Massachusetts are generally compartmentalized within departments serving specific constituencies. Aside from DPW funded PCA services, people with disabilities may access the ILC managed PCA system in two other ways: (1) Through the state's insurance system for people with disabilities, Commonwealth Extra. Although there are no income or asset limits, there is a sliding scale. (2) The MRC offered PCA services for working people with disabilities. Since Commonwealth Extra has been created, the MRC has closed intake. The MRC also provides up to 10 hours per week of basic homemaker services for roughly 1100 working age individuals with disabilities.

Older disabled people are generally not served by the PCA program (only 7% of the 1989 PCA caseload was over 65). They tend to use services in the Department of Elder Affairs are coordinated through local Area Agencies on Aging (AAAs). Many elderly people, particularly couples, cannot meet current Medicaid income eligibility requirements. There is a Medicaid Waiver for people over 65, which served 3381 clients in 1990. The waiver has more generous income eligibility, but funds are very limited. In 1974, 27 state-funded homecare corporations were combined with AAAs, and these function as independent assessment and case-management agencies. The AAAs contract with provider agencies for provision of PAS and homemaker services. In the current fiscal crisis, AAAs have had to cut off services to "the least frail" consumers, and institute across the board service cuts. The state spends roughly \$1 billion on nursing homes per year. A pilot pre-admission screening program run by three AAAs was so successful that the program was expanded statewide this year. However, an AAA administrator observes that "there is nothing to divert them into", i.e., homecare is so limited that it cannot be a viable alternative to nursing home placement. Adult foster care is utilized by some older people with disabilities.

The Department of Mental Retardation (DMR) has historically relied on a costly system of ICF/MRs and state schools, but this system has been called into question by DD advocates such as ARC. A recent study commissioned by the governor says that

nine "state schools" for people with mental retardation were built to house 10,000 people are currently housing only 2,600 with a staff to client ratio of three to one. The study recommends closure of these facilities and placement of residents into community facilities. A large DMR Waiver (which served 14,024 people at a cost of \$49 million in 1990) has redirected a significant percentage of funding into community services. Smaller group homes are being expanded, and other resources such as adult foster care and more individualized "adult family care" are being developed.

As previously noted, the state has modified its regulations to allow for PCA services to people with supervision as well as personal care needs. A local ARC agency has been approved as a PCA coordinating agency which will offer the surrogacy model, and advocates hope PCA services can ultimately be extended to the following groups:

- people with cognitive disabilities living in the community with aging parents.
- people coming out of special education at age 22, who would probably have been picked up by state funded programs (such as sheltered workshops) before the budget cuts.
- residents of schools for those with behavior problems (those with both physical disabilities and mental disabilities).
- people living in group homes who could become more independent over time and move to their own apartments.

B. Who is Failing Through the Cracks?

Massachusetts offers extensive services to most people with disabilities, but these services are not comparable across populations. The ILCs' traditional constituency is young people with disabilities, and this is reflected in the PCA caseload breakdown. People with cognitive disabilities or older people who could probably benefit from the independent living orientation of PCA services do not currently access the program, and may end up in far more restrictive services. Advocates for people with AIDS/ARC are beginning to look at PCA services, and the state would like to designate an AIDS service agency as a PCA coordinating agency for this growing population (as an alternative to more costly services such as home health). DD advocates say that the relatively small number of PCA providers limit access to all people with disabilities who are not residing in a geographic area served by an ILC, but an advisory council member points out that Massachusetts is a relatively small state and geographic access is not a big issue.

People who rely on solely state funded agencies are most likely to fall through the cracks in the current economic crisis, hence the concern over consumers in both the Department of Elder Affairs and the DMR. AAA administrators say that their system is in crisis as resources shrink and populations grow both in number and in severity of disability. However, the present concern over expenditures may in fact lead to more comprehensive community based services, as the state looks for ways to contain soaring institutional costs.

C. The Political Future of the Personal Care Program

The federal match is making the personal care option an increasingly attractive funding source for services to different disability groups. The most vocal to this point have been the DD advocates, but there is an enormous need for expansion of PAS in the state's senior services system. An AAA homecare agency has applied to become a PCA coordinating agency, and others will no doubt follow. There is some talk of using PCA services in the state's rest homes for the elderly.

At this point, both the DPW and the ILCs seem to be resisting the pressure for expansion of the PCA program. The surrogacy issue is symptomatic of this struggle. How can Massachusetts increase services to people who need them, while maintaining the unique features of consumer control that define the service delivery system? Can the state afford such an expansion?

There are no easy answers for these questions. A growing number of advocates are saying that the ILCs should get out of the business of service provision altogether, that the ILCs are becoming "Medicaid mills" instead of advocacy resources. The fact that the PCA program has become the primary source of revenues for several ILCs suggests that there is some truth to this argument, but also makes it unlikely that these ILCs will abdicate their service provider roles. Advocates among the ILCs are clearly split on issues of surrogacy and attendant withholding. Representatives of different disability groups such as the DD advocates are often at odds with the ILCs on many PAS related issues.

The friction between the DPW, disability advocates and other state agencies on issues such as surrogacy is understandable, given the current climate of crisis. To this point, the DPW's main responsibility for the PCA program has been to reimburse the ILCs. During the interviews, there was a palpable sense of anxiety among DPW administrators as they braced for new staffing cuts. Moreover, HCFA representatives have singled out the PCA program as discriminatory and poorly managed. Proposals requiring increased administrative commitment and greater expenditures will therefore undoubtedly be viewed with trepidation by the beleaguered DPW staff.

Despite the impediments to cooperation among advocates and state agencies, cooperation is precisely what is required for the program to weather the current crisis. Massachusetts' PCA program is nationally recognized by the disability movement as a model of consumer control, and the state administration is struggling to maintain this focus. Figuring out how to facilitate provision of consumer controlled PAS in a cost-effective manner to people of all ages and all disabilities has thus far eluded all states, but Massachusetts has probably come the closest. If the impacted groups are willing to coordinate and consolidate their resources, there is a potential for an extraordinary system of community-based service delivery.

Individuals Interviewed

Department of Public Welfare:

- Russ Kulp, Director of Ambulatory Programs
- Tom DeVouton, Assistant Director for Provider Programs
- Janet Pearlman, Ambulatory Programs
- Maria Verbeyst, PCA Program Manager
- Diane Flanders, Director of Community Program Management

Department of Vocational Rehabilitation:

- Karen Langley

Northeast CIL:

- Charlie Carr, Executive Director

Independence Associates:

- Paul Spooner, Community Development Coordinator
- Jim Brown, Director of Services

Center for Living and Working:

- Dennis Fitzgibbons, IL Coordinator
- David Murphy, Training Coordinator

Boston Center for Independent Living (BCrL):

- Bonnie O'Day, Executive Director
- Paul Tupper, PCA Coordinator
- Eric McCall, BCIL staff
- Jim Tierney, BCIL staff
- Pete Cronis, BCIL staff
- Brenda Clarke, BCIL staff

Stavros ILC:

- Dan Greaney, Director of PCA Services and PCA recipient
- Roma Roukey, Stavros Staff and PCA recipient
- Kathy Shagnon, Stavros Staff and PCA attendant

Other PCA Consumers:

- Kevin Duby
- Diane Layman
- Henry Marchal
- Michael LeGare

PCA Attendant:

- Mike Owens

Association for Retarded Citizens:

- Gerry McCarthy
- Phil Campbell

Boston Center for Self Help:

- Connie Panzarino
- Judy Brewer

Independent Living Resources:

- Chris Palamos
- Judy Kimberly

Franklin County Home Care Corporation, Local AAA

- Pat Kerrins, Executive Director

MARYLAND MEDICAL ASSISTANCE PERSONAL CARE PROGRAM

Administered by: Maryland Department of Health and Mental Hygiene

Date of Site Visit: January 28 to January 31, 1991

NOTE: THIS REPORT REPRESENTS THE ONLY PROGRAM IN WHICH THE STATE ADMINISTRATION DID NOT RESPOND TO THE DRAFT OF THE PROGRAM DESCRIPTION. IT IS THEREFORE POSSIBLE THAT SOME OF THE INFORMATION REPORTED HERE IS NOT ACCURATE.

I. Program Overview: Size of Population and Expenditures, Program Objectives

The Medical Assistance Personal Care (MAPC) program is administered by the Long Term Care Division of the Department of Health and Mental Hygiene (DHMH). The program budget was \$14.8 million in FY 1989, and served 5254 people. Program expenditures are projected to be roughly \$19.9 million in FY 1991, but the state has asked the DHMH to look at ways to cut the program budget by 13 % to 50 %. Roughly 10% of program expenditures goes to case monitoring functions, and 2.5 % to administration. The remainder goes to provider pay.

The program serves Medicaid eligible people who live at home and need assistance with activities of daily living (ADLs). The program assigns recipients to three levels of need: some daily ADL needs (level I), extensive ADL needs (level II), and ADL needs at all times (level III). The program pays independent providers a daily rate of \$10 for level I recipients, \$20 for level II recipients, an \$25 for level III recipients. Functional eligibility determination, needs assessment and case-management are performed by independent RNs or RNs working for county public health departments.

The program's objectives are to support informal caregivers and prevent or delay institutional placement. There is widespread dissatisfaction with the program's current structure on the part of the state providers, providers, consumers and advocates. This dissatisfaction, in the context of Maryland's fiscal crisis, suggests that major program policy changes are possible in the near future.

II. Program History

The Department of Health and Mental Hygiene started the Medical Assistance Personal Care program in 1981 in order to curtail nursing home admissions. The

program was based on the personal care program in Oklahoma. It paid a flat rate of \$9 per day per client, and according to DHMH representatives, was intended to supplement the clients' existing informal support systems (i.e. friends, neighbors). The decision to implement the program was apparently made without extensive planning or consultation with other state departments, and to some degree duplicated the services of another state program, In-Home Aide Services (IHAS), administered by the Department of Human Resources (DHR). In order to justify the new program to the state legislature, the DHMH had to demonstrate that services were not being duplicated. A decision was therefore made to transfer people in the IHAS program who were income eligible into the MAPC program. This had the advantage of accessing uncapped federal matching funds for clients who were until this point served with limited Title XX and state funding.

The assumption that the \$9 stipend would go to informal supports was soon disproved a state survey showed the majority of service providers had no personal connection to recipients' prior to their employment. The DHMH had, in the words of one administrator, created "a cottage industry" for PAS providers and nurse case monitors. As the state medical services branch, the DHMH was unprepared for the rush of applicants for the service. It became apparent that the MAPC was filling a vacuum in state services for people with disabilities. Many of these services were traditionally what the state would consider "social services", which the DHMH had no experience or desire to provide. Moreover, the stipend was clearly not sufficient to meet the scope and depth of consumer need.

One suggestion was to bring MAPC in line with the DHR's IHAS program, by creating an hourly wage for attendants. However, the DHMH feared that hourly payments could be a factor in identifying the department as the legal employer for a large and growing number of providers of an entitled service (i.e. Medicaid eligible could not be refused PAS services, so there was no simple way of capping the caseloads).

In order to cope with the extensive needs of some MAPC consumers, the DHMH decided to categorize recipients by three levels of need and offer daily reimbursements based on these levels (a fourth level has recently been added for high need people with AIDS, but this has not been utilized as yet). This decision had the advantage of recognizing the different needs of consumers while avoiding an across the board raise to providers. By keeping the daily wage rate structure, the DHMH strengthened its case (should it be challenged), that it is not the attendant's employer. The daily rates remain so low, however, that high need consumers still cannot get adequate PAS.

The MAPC program has continued to grow dramatically; current expenditures are over 400% of what they were in 1984. Ongoing frustration with program inadequacies has led to the formation of a group called Marylanders for Adequate Attendant Care (MAAC). Within the state government, complaints about the MAPC program were the subject of legislative hearings. The Governor's Council on Handicapped Individuals (GOHI) has also examined the issue, but some advocates complain about this group's

failure to issue strong policy directives for program reform because of cost considerations.

The state of Maryland faces a large budget deficit, and the growth of Medicaid in general and specifically personal care is viewed with alarm by both the legislature and the governor's office. Directives have been issued by the governor's office to cut expenditures, and DHMH officials anticipated slashing program expenditures by up to 50%. This has led to an extraordinary consumer backlash, led by members of MAAC. They have conducted demonstrations and acts of civil disobedience in order to draw attention the MAPC program.

III. Gatekeeping and Supervision Functions: Eligibility, Needs Assessment, Case-Management, Medical Supervision

A. Eligibility Determination

Income eligibility for Medicaid is determined by the state. Current Medicaid income eligibility is set at 74% of poverty level. Nurse Case Monitors are responsible for determining medical eligibility. Eligibility is based on functional limitations with activities of daily living (ADLs), and there is an appeal procedure for individuals who are denied eligibility. There is no formal scoring system: functional eligibility is based on professional discretion. The assessment is sent to the applicant's doctor to see if s/he concurs with the case monitor that PAS would be appropriate for the applicant. The doctor must have seen the applicant within the past 6 months.

State administrators suggest that because there is no reimbursement for doing eligibility assessments unless the client is deemed eligible, there may be a tendency to allow people into the program who have a relatively low degree of functional limitation. The lack of explicit medical eligibility criteria was indicated by the state as one reason for the program caseload growth which has occurred.

B. Needs Assessment

During the eligibility determination, the nurse case monitor assigns a level of need: some daily ADL needs (level I), extensive ADL needs (level II), and ADL needs at all times (level III). A fourth level has been developed for people with AIDS who need very high levels of skilled care (i.e. home health aides), but this has not been implemented as yet. Advocates point out that the levels of service are clearly inadequate, especially for clients with a high degree of functional limitation. The state seems to concur, and is considering eliminating level I entirely, in order to cut costs and provide more resources for level II and III consumers.

C. Case Management

Nurse case monitors are required to visit recipients every 60 days. During this visit, they review the plan of care, assess the need for service, and monitor the attendant.

In 10-12 counties, the local health department hires nurses on a contract basis, but in most counties several independent nurses compete for clients. Some nurses have become entrepreneurs, forming agencies and maintaining a staff of nurse case monitors. They each may have case loads of up to 50 people, and are reimbursed \$40 per month per active case. There are clear financial incentives for keeping caseloads near this level, and this is also identified by state administrators as a factor in program growth.

D. Medical Supervision

A physician must authorize services annually. The nurse case monitors check the medical condition of consumers during their review of the consumer's plan of care every 60 days.

IV. Service Limits

A. Total Services Allowed Per Consumer

There is no explicit limit for services per consumer, but the daily reimbursement rates are a de facto limit on services. The nurses say that the payment rate is roughly \$5 per hour, therefore level I clients should get 2 hours of service per day, level II clients get 4 hours of service per day, and level III clients get 5 hours per day. There is no real assurance that the consumer receives even this level of daily service. At one public housing project, level III consumers have formed a co-op in order to pool resources and have access to an on-call attendant.

B. Type of Services Offered

1. Paramedical Services

Paramedical services are not allowed in this program. Medications which are "ordinarily self-administered" can be given by the attendant, but because many of these clients are poor and do not have access to adequate health care, nurse case monitors say they must spend a lot of time explaining medication regimes to consumers and attendants.

2. Emergency and Respite Services

There are no mechanisms for provision of emergency or backup services in this program.

3. Homemaker Services

Household services "directly related to medical need and essential to the recipient's health and comfort" are provided by the program.

4. Supervision

Eligibility for the program is defined broadly enough to allow recipients with supervision needs to receive services. One program in Baltimore called Prologue Inc., has apparently had remarkable success in using MAPC services to prevent recurring institutionalization of psychiatric clients.

C. Location of Service Provision

Services are limited to the home or non-institutional settings (i.e. small group homes with less than 4 clients). There is some discussion with the state Developmental Disabilities Administration about using MAPC for other types of group homes, but the DHMH seems reluctant to expand the program.

The program allows for escort to medical appointments, but because the program does not allow reimbursement for transportation expenses and does not allow the attendant to transport the consumer, medical appointments are often missed. The problem is related to the larger crisis in medical services: since all recipients are well below the poverty line, they must rely on inadequate public medical care. In the words of one case monitor, "Nobody is going to take a person on the bus, go to the emergency room, and wait for 5 hours if they're only getting \$10 for the day."

V. Support Services Available

A. Attendant Management

1. Attendant Recruitment

The consumer is primarily responsible for recruitment, but nurse case monitors say they spend a lot of time and resources helping with recruitment. Local unemployment offices often refer potential applicants. Applicants go through a standard screening at the state level. The DHMH enrolls 30-60 new providers per week.

2. Attendant Screening

The state maintains a record of attendants with a history of abuse and incompetence; this includes individuals who have been fired from nursing home jobs. The applicant's social security number is checked against this list before hiring occurs. The attendant must also provide two letters of reference and a photo ID, be over 18, and have a physical examination to verify that they are capable of physically performing their duties. Nurse case monitors have some "veto power" if they believe the applicant is unsuitable.

3. Attendant Interviewing

The consumer is responsible for interviewing the attendant. S/he ultimately decides whether or not to hire the attendant, but in practice the pool of applicants is so small that consumers are often stuck with whoever they can get.

4. Attendant Certification

No certification of attendants is required.

5. Attendant Hiring

The client is ultimately responsible for hiring. A standard contract is signed by the consumer, attendant, and case monitor, which explicitly states that the attendant is self-employed. The contract is then reviewed by the DHMH.

6. Attendant Training

The case monitor does some attendant instruction. Formal one day trainings are available in some counties.

7. Attendant Supervision

Case monitors are responsible for attendant supervision during the 60 day reevaluations, but consumers are encouraged to call if there are any problems. Case monitors say they spend a lot of time responding to such calls.

8. Attendant Payment

The provider completes an invoice which s/he submits to the DHMH. Case monitors must sign these invoices, but they often pre-date invoices, which opens a potential for fraud (i.e. the attendant bills for days service was not provided, or continues to bill the state after being fired). It is difficult to assess the frequency of this, according to advocates and the DHMH, because the consumers are hesitant to report abuse for fear of being left without an attendant at all. One case monitor interviewed now refuses to pre-date invoices because of several experiences with fraud.

9. Attendant Termination

The consumer is responsible for attendant termination, but may be hesitant to fire an incompetent or abusive attendant because of the difficulties associated with hiring and retaining attendants. Terminated attendants will only go on the state "blacklist" if the case monitor reports them.

10. Conflict Resolution

Case monitors are the main resource in resolving conflicts between consumers and attendants.

B. Consumer Support

1. Consumer Advocacy

The nurse case-monitor may function as an advocate, but there is no source of consumer advocacy outside the service delivery system, although some groups such as ARC may intervene in some cases.

2. Consumer Training

No consumer training is offered by this program.

3. Consumer Outreach

No formal mechanisms exist for consumer outreach, although there appears to be widespread knowledge of and use of the program among the state social and medical service systems through the nurse case monitors.

4. Quality Monitoring

Case monitors conduct a formal provider evaluation during the 60 day assessment. There is little systematic overview of quality other than this procedure. Advocates suggest that there is tremendous variability among services between counties.

VI. Attendant Issues: Family Providers, Wages, Benefits, Withholding

A. Family Provider Regulations

Family members are not allowed to become providers. Family is broadly defined as spouse, parent child, stepparent, stepchild, aunts, uncles, cousins, nieces, nephews, in-laws. Grandparents apparently can become providers. Several nurse case monitors

inter-viewed said that a relaxation of these rules would increase quality of services and make recruitment easier.

B. Attendant Wages

Roughly 90% of program expenditures go to provider wages. The program pays independent providers a daily rate of \$ 1 0 for level I recipients, \$20 for level II recipients, or \$25 for level III recipients. The state limits the amount of recipients that can be served by a single provider. The provider is allowed work for up to four level I clients at the same time, or two level I and one level II client. They can also work for two level II clients, or one level II and one level III client, if both clients share a single residence.

The low pay makes it very difficult to hire and keep high quality attendants. According to advocates, many consumers recognize the pay is unreasonable, so they are more tolerant of fraud and abuse. One consumer reports giving medication for the attendant to sell in order to supplement his wages. Adding to the low pay problem is the delay of 4 to 6 weeks between submission of an invoice and payment. This delay is a source of frustration for attendants and case monitors. Attendants monitored by local health department nurses are able to get paid sooner, because the health department advances payment while waiting for state reimbursement.

C. Attendant Benefits

No benefits are provided by the state.

D. Withholding and Liability Issues

The attendant is considered self-employed, and this is stated in the hiring contract. The DHMH sends out 1099 forms which go to the attendant, who is responsible for withholding. Several causes have been brought by providers which tried to establish the state as the employer and responsible for worker's compensation, but they were not successful. The daily pay rate is offered as evidence that the attendant is not a regular state employee, but an independent contractor. Concern over liability has deterred the DHMH from switching to an hourly rate.

The state has never been sued for negligence. A case monitor was sued because the provider failed to follow the plan of care, but the case was settled out of court. The DHMH is concerned with potential liability in assistance with medications, and is considering dropping this task from the list of allowed services.

VII. Program Context: The Relation of Medicaid Personal Care to the State Service Delivery System as a Whole

A. An Overview of Other State Programs

The Department of Human Resources operates a state funded PAS program called In Home Aide Services (IHAS), which served 3,407 clients per month in FY 1989 and had expenditures of roughly \$13 million. Recipients can receive up to 20 hours of service per week unless service is necessary to prevent imminent nursing home placement or abuse or neglect. In these two cases, services are provided as needed up to a cost cap of 67% of the average statewide public cost of nursing home care. Services are provided by salaried state employees, private or nonprofit agencies, and self employed individuals. Self employed attendants may be family members in certain situations. The program is not an entitlement, and there is an extensive waiting list (2,776 persons in 1990). The DHR ranks cases according to risk of institutionalization, and must withdraw services from current recipients who are not at risk of institutionalization when a person at risk is placed on the waiting list. Transportation, respite, escort and chore services are offered, as well as personal care. The population served by IHAS tends to be older and somewhat less poor than the MAPC recipients.

The IHAS program is often cited as a contrast to the MAPC program by advocates pushing for reform of the Medicaid program, but "both have their problems." According to advocates, neither program is really adequate to the needs of people with severe functional limitations. In order to assure the state legislature that there is no duplication of services between the DHMH and the DHR and that federal matching payments are captured whenever possible, anyone eligible for MAPC services is referred by DHR to MAPC. IHAS regulations allow anyone who "is unable to obtain the necessary paraprofessional services from another resource" to receive IHAS services and about 100 Medicaid eligible services are receiving IHAS for this reason. If a MPCP provider became available, these MPCP eligible persons would be transferred to MPCP to take advantage of the federal matching payments and increase the total number of persons who could be served by attendant programs.

The state Office on Aging administers a \$4-5 million state funded program for personal care and chore services for older people. The Department of Vocational Rehabilitation offers a very small state program (37 clients) for people who are either employable or at risk of institutionalization. The program is not a major provider of attendant services in Maryland. It is small (37 clients in comparison to the 4000+ served by the DHMH and DHR), 100% state funded, and capped by the state allocation each year. There are rarely openings in this program; 95% of recipients who began with this program are still receiving its services.

The DHMH currently has three Medicaid waivers: (1) A model waiver for elderly people, which allows for case loads to increase in increments of 50, and is therefore considered "very manageable" by administrators, (2) A waiver for technology dependent children, and, (3) A community service waiver for people with mental retardation in ICF-

MRs. The last is a cold bed waiver (tied to the number of people removed from ICF-MRs) which is intended to facilitate deinstitutionalization. The department sees the waivers a way to "focus resources" for specific populations, but do not see this as a viable funding base for a large-scale program.

B. Who is Falling Through the Cracks?

There are a number of populations who are unserved or underserved in Maryland. These groups include:

1. Persons 18-64. Although there are waiting lists for attendant for persons of all ages, the state budget sets aside special funding in both the DHR and Office on Aging budgets to be used for community based service only to persons 65 and older.
2. Any person who needs more than a few hours of PAS per day. These include people who use ventilators, people with Alzheimer's or AIDS.
3. People who work. There are tremendous work disincentives in the present system.

C. The Political Future of the Personal Care Program

The state, providers, recipients, and advocates are all clearly unhappy with the present structure of the program, but no major changes are planned for the coming year. The MAPC program, despite its growth, remains a relatively small part of the DHMH services, but it requires a growing amount of administration and coordination. Moreover, it is garnering a tremendous amount of political attention from the public, the legislature, and the governor's office. DHMH administrators express frustration with both the administrative demands and political heat, but feel bound by budget considerations from taking significant action. They are told by the governor's office that any policy reforms must at least be cost-neutral, so changes are constantly couched in the terms of a "more services for fewer people, or more people for fewer services" dichotomy.

There is little doubt that the program currently seems designed to serve best those who are least in need, but the program has come to fill an important niche in the service delivery system for relatively less disabled individuals, and removing services would certainly cause disruption for many of these recipients. The DHMH reports that some cases service applicants are pregnant or are recent mothers who simply want help with child care (they were of course denied). Such incidents show how this unstructured program has come to be viewed as a solution to a plethora of social service needs.

A DHMH proposal to drop all level I clients and increase level II and III reimbursement rates met with stiff opposition, and brought charges of attempting to "buy off" the people with high degrees of physical disability who make up the core of the consumer movement. Other advocates say it is foolish to remove services to the only people who are really benefiting from the program, especially if these people must then

receive services through the state funded and overloaded social service system (e.g. the people with MI currently being served by Prologue Inc.).

DHMH administrators believe that resources need to be refocused to those who are most in need (i.e. DD, MI, Aged going to nursing homes, physically disabled with high ADL needs), but are at a loss as to when and how they will make this shift. The state Developmental Disabilities Administration (DDA) is pushing for a broadening of eligibility in order access to the federal match for its' community based residential programs. The DHMH questions whether the MAPC program with it's untrained attendants is appropriate for this population.

The DHMH administration seems interested in moving to a private agency model. In the view of state administrators, agencies would be responsible for hiring, training, and supervision of attendants as well as other administrative functions, and the DHMH could return to the role of overseer and rate setter (with which it is clearly more comfortable). The increase in expenditures required for the switch would be prohibitive at this point, unless the total caseload is cut through stricter eligibility requirements or some other mechanism. Underlying problems such as adequacy of service, degree of consumer control, and scope of services would not necessarily be addressed by a private agency model.

Members of Marylanders for Adequate Attendant Care (MAAC) and the advisory committee of Governor's Council on Handicapped Individuals have come up with a detailed proposal for overhauling the state's PAS system. The proposal creates a single PAS program which eliminates eligibility restrictions on age, income and employment status. A sliding fee scale would be established, and consumers would have a choice of independent providers, home health agencies or state employees. A residential center would be established for people that need 24 hour PAS with a supervisor for the attendants. A benefit coordinator would assist residents to obtain all federal and state benefits for which they are eligible. The proposal is an impressive attempt to consolidate PAS programs while maximizing consumer control. Political inertia and the estimated \$5.1 million required for implementation or the necessity of limiting services only to those most in need may unfortunately preclude this reform package.

At least in the short term, the state seems determined to focus on cost containment and political damage control instead of developing a consensus for policy action. Advocacy groups such as MAAC are committed to keeping up political pressure, so attendant services will continue to be a hot issue in Maryland.

Individuals Interviewed on Site

Maryland Department of Health and Mental Hygiene:

- Lawrence Payne, Director, Medical Assistance Compliance
- Joseph Millstone, Director, Medical Assistance Policy

- Mark Leeds, Chief of Medical Care Policy Administration, Division of Long Term Care
- Samuel Colgaine, Chief of Medical Care Compliance Administration, Division of Long Term Care
- Tom Coplin, Regulations Specialist, Division of Long Term Care
- Mike Franch, Researcher, Aging Services Coordination Unit
- Carol Settlerman, Chief of Community Care Unit, Division of Long Term Care

Maryland Office on Aging:

- Ted Grey

Health Planning Commission:

- Evelyn Buff

Independent Nurse Case Monitors:

- Beatrice Morris, RN
- Barbara Bailey, RN
- Shirley Patterson, RN
- Irnistene Jefferson, RN

Washington County Health Department:

- Linda Humbert, Director of Nursing
- Patricia Boyd, Supervisor of Adult Health Services
- Mark Jameson, MD
- Katherine Bennett, RN Case Monitor
- Helen Hull, RN Case Monitor

Personal Care Consumers:

- Sandy Prince
- Bonnie Barker
- Ellen Alexander
- Inez Smith
- Aristel Whety
- Robert Tucker
- Mildred Louis
- Walter Horten
- Allen Jones
- Iole Perry

Marylanders for Adequate Attendant Care (MAAC):

- Ellen Leiserson, LCSW
- Nathan Butler, IL Specialist, Maryland Center for Independent Living
- Jack Prial, Information Specialist, Maryland Rehabilitation Commission
- Debbie Grubb, Governor's Council on Handicapped Individuals (GOHI) representative

- Tom Condon, former GOHI president
- Joel Myerberg, director of Franklin Center Consumer Cooperative

Association of Retarded Citizens (ARC):

- Anna Marie Pool, Director of Independent Support Services

Office on Disabled Citizens:

- Cindy Meese, current GOHI chair

Maryland Disability Law Center:

- Steve Ney, JD

TEXAS PRIMARY HOME CARE PROGRAM

Administrative Agency: Texas Department of Human Services

Date of Site Visit: February 22 to March 1, 1991

I. Program Overview: Size of Population and Expenditures, Program Objectives

The Texas Primary Home Care (PHC) Program is administered by the Texas Department of Human Services (TDHS) through the Community Care Section of Aged and Disabled Services (CCAD). It is the second largest Medicaid PC-Option program in the country, serving an average of 32,500 people per month, with total direct service expenditures of roughly \$119,000,000 in FY 1990. It serves Medicaid eligibles who need at least 6 hours of assistance with activities of daily living, and services are capped at 30 hours per person per week. Services are coordinated at a regional level, and multiple private provider agencies are contracted in each region.

The program was created primarily in response to the state's decision to eliminate reimbursement for low medical need (ICF Level II) nursing home clients. The program's objectives are to provide cost-effective services for these individuals in the home community rather than in institutions, and to bring "care to those who could not access custodial placement". It was conceived as a large scale PAS program able to meet the needs of a wide range of individuals and access federal matching funds.

II. Program History

Prior to 1979, attendant services were funded solely by Title XX funds in Texas. Independent providers were recruited by caseworkers, and these attendants were paid by the state at below the minimum wage. Because Title XX revenues began to diminish, the state decided to include Personal Care in the state Medicaid plan in order to capture the federal match.

This occurred at the same time that the Texas legislature was faced with projected increases in the nursing home population. A report from a Blue Ribbon Panel recommended that the state: (1) Close down custodial care (ICF II) facilities, and (2) expand the number and types of community programs.

In order to facilitate the placement of ICF-II clients in the community, the state received a Medicaid 1115 Waiver. The waiver allowed continued Medicaid eligibility, and therefore access to the federal match, for those nursing home clients who had an ICF II level of care prior to 1980. It also allowed those who met the income criteria for

Medicaid reimbursement in a nursing home to be financially eligible for personal care services reimbursed by Medicaid. These clients, as well as clients who met regular Medicaid financial eligibility requirements, became eligible for a new program called Primary Home Care. All ICF II admissions were shipped, and despite some industry prognostication, there was no demand to re-open these nursing homes. The 1115 waiver is running out in June of 1991 (see "Political Future", section VIIIc, below for a discussion on the implications of this loss of funding).

In order to meet the needs of the ICF II population, the state also developed adult day health, emergency response services, and residential care in licensed PC-homes (board and care). They expanded foster care, meals on wheels, and special service programs.

Primary Home Care was designed as a private vendor system, where multiple agencies agree to rates and regulations set by the DHS. This process has led to the development of a fairly cohesive industry lobby, the Texas Association of Home Health Care Agencies. Only agencies with certified home health divisions are allowed to provide personal attendant services. The DHS believes that this arrangement assures that the legal entity has the demonstrated capability to deliver services in the home, and ensures that the consumer has ready access to a skilled care delivery system if s/he needs it. There are currently 180-200 vendors statewide. The system of "open enrollment" contracting allows the client to choose from among the private agencies available in his/her region. The DHS believes that this competitive system encourages service quality.

A uniform reimbursement rate covers services throughout the state. According to DHS administrators, cost differences between rural and urban areas tend to level out. Agencies deliver more units (hours) of service in the big cities and RN supervisors do not need to travel as much to do home visits, which leads to economies of scale (even though they need to pay slightly higher wages). Salaries aren't as high in less populous areas, which offsets the lower volume.

An functional eligibility instrument which assessed limitations in activities of daily living (ADLs) was developed and refined. In order to contain program growth, the ADL score for program eligibility was raised in 1986. State administrators feel that the current level is adequate to separate out those who really need PAS, and are able to defend this to the state legislature. The state also changed the per client service limit from 20 hours to 30 hours per week. According to state administrators, this development did not "lead to a, stampede" for more hours.

Program procedures and regulations were developed and refined, and a compliance monitoring system was developed to evaluate provider agencies. This process of program development continues, and the state is currently looking at mechanisms for providing higher levels of service, emergency services, and paramedical services to consumers.

III. Gatekeeping and Supervision Functions: Eligibility, Needs Assessment, Case-Management, Medical Supervision

A. Eligibility Determination

Three major groups are involved with eligibility determination: regional case managers, regional prior approval nurses, and agency nurse supervisors. The caseworker determines income eligibility and functional eligibility. Medicaid income eligibility in Texas is set at 74 % of poverty level for individuals.

The agency nurse does a detailed medical assessment, linking diagnosis and functional need. After all documentation is turned into the regional office, the regional Medicaid nurses review all documentation to determine that there is evidence of a medical need, and that the tasks authorized are within the program's definition of nonskilled services given the medical condition of the client. After the regional nurse gives prior approval, the agency has up to 7 days to begin service delivery.

A functional assessment tool is used to determine limitations with activities of daily living (ADLs), and the score is used as one of the eligibility screens. It consists of an inventory of twenty activities, which were chosen because they were the "best predictors of need for the community care the programs provide." The case manager rates the client from 0 (no functional impairment) to 3 (total functional impairment) on each activity. Assessment is based on what an individual can do at the point of waking - e.g. can the individual get him/herself out of bed and in position to be able to cook, rather than, can s/he cook once she is in position to be able to cook. State administrators consider the measures both objective and reliable.

The functional eligibility level was increased, from a low of 18 ADL points to the current 26, in order to contain program growth. State studies have shown that almost all those with a score of 26 need direct personal care as defined in the PHC program. The eligibility level has remained at 26 since 1986, because the program has convinced the legislature that raising the level above 26 would jeopardize peoples' health. Recipients must also need at least 6 hours of PAS per week to receive services.

B. Needs Assessment

While the initial needs assessment involves medical condition and functional ability, a detailed service plan takes into account other supports the individual may have in the household. If the caseworker thinks that adequate family supports are available, the applicant may be denied services. The service plan is developed with the caseworker and agency RN supervisors and the prior approval nurse determines that the service plan concurs with the assessment and recommendations of referring physician.

C. Case Management

Regional case managers have an average caseload of 140 Primary Home Care recipients. They are required to have a college degree and/or related work experience. They do initial intakes, needs assessment, and work with agencies to develop service plans. They are required to do at least one home visit every 6 months (although more visits frequently occur). Agency nurses often function as case-managers as well, because of their direct contact with the recipients and attendants.

D. Medical Supervision

The physician can authorize services for up to six months, but may authorize for shorter periods of time if s/he thinks that frequent medical visits are necessary. This requirement was considered excessively stringent by some nurse supervisors and case-managers for consumers with chronic but stable conditions.

The agency nurse supervisors are required to do home visits every 60 days, but often do visits more frequently. A detailed nursing assessment must be done every 6 months. Medicaid prior approval nurses each do an average of 50 home visits per quarter as part of their utilization review activities.

IV. Service Limits

A. Total Services Allowed Per Consumer

Services are limited to 30 hours per week in the Primary Home Care program. This service limit is a controversial program feature, especially among disability groups like United Cerebral Palsy (UCP).

B. Type of Services Offered

1. Paramedical Services

Attendants are not allowed to do invasive procedures such as irrigate internal catheters, give injections, or give medications. They may change ostomy bags, tampons, or external catheters. Disability advocates have successfully lobbied for revision of regulations promulgated by the state Board of Nurse Examiners. These revisions theoretically allow nurses to delegate paramedical tasks to paid attendants, but these changes have not impacted state programs at this point. In a few state-funded programs, the doctor may delegate tasks directly to an attendant. There is concern among state administrators and industry representatives that provision of such services constitutes a liability risk. A DHS administrator also observes that since all provider agencies also have certified home health divisions which can bill at a much higher rate, there is an economic disincentive to modify service delivery practices.

2. Emergency and Respite Services

Both advocates and state administrators identify "service gaps" as a major problem. Currently, agencies may take up to 14 days to provide an attendant once the consumer is deemed eligible, or when consumers change agencies and/or attendants. This can be disruptive or dangerous for consumers with a high level of need. Both private agencies and DHS workers claim that high need cases receive an immediate or expedited response. However, disability advocates know of clients who, because an attendant fails to show up and they have no informal support for backup, have become enmeshed in the Adult Protective Services system and ultimately are forced back into an institutional settings. Administrators are meeting with advocates and vendors about the service gap issue, and plan to submit a recommendations to the DHS board by August of 1991.

3. Homemaker Services

Basic homemaker services for the consumer are part of many consumer service plans.

4. Supervision

Supervision is not provided as a regular service in Primary Home Care.

C. Location of Service Provision

Service is limited to the home and to medical visits.

V. Support Services Available

A. Attendant Management

1. Attendant Recruitment

The private nurse supervisor is primarily responsible for this function. S/he is often assigned all consumers within a certain geographic area, and intensive recruitment occurs within this area. Various techniques a-re used to attract potential employees, from newspaper advertisements to posting notices in grocery stores and churches, to (in extremely rural areas) knocking on neighbors' doors.

2. Attendant Screening

Agencies will call employer and personal references. The state runs a criminal check on potential attendants, but hiring usually occurs before the results are available. Convicted felons are not allowed to become attendants.

3. Attendant Interviewing

The agency does initial attendant interviewing during the screening process, but the client is involved in interviewing and hiring.

4. Attendant Certification

No programmatic certification is required, although there is some discussion of developing certification requirements for special attendants, who would then be able to perform certain paramedical tasks.

5. Attendant Hiring

After an initial screening, the potential attendant is called in for a meeting with the RN supervisor in the client's home. The client is ultimately responsible for deciding if the attendant is hired, but some consumers say that this choice may be couched by the nurse supervisor with observations like "people who accept these wages are hard to find". These observations may be accurate, but ultimately limit real consumer choice. When hiring is done, it is usually described as conditional, pending a criminal check and satisfactory performance of job duties.

6. Attendant Training

The RN supervisor will work with the attendant if any tasks require special training. The nurse must also explain medical conditions and special medical and dietary requirements of the consumer.

7. Attendant Supervision

The case manager, RN supervisor, and prior approval nurse all may be involved in, attendant supervision. Case-managers and RN supervisors both call and drop-in to make sure the attendant is there and is doing the assigned tasks. Consumers complained that unscheduled drop-in visits by nurses and case monitors can be disruptive, and seem to imply that the consumer "has nothing better to do than wait by the phone or door".

8. Attendant Payment

Agencies are responsible for this function.

9. Attendant Termination

Either the consumer or the RN supervisor may terminate an attendant.

10. Conflict Resolution

Most conflict resolution between consumers and providers is done informally with the case manager or RN supervisor, but formal resolution may involve the consumer, attendant, caseworker, RN supervisor and prior approval nurse. Once a vendor is chosen, the recipient cannot change vendors until the next case-manager assessment (every six months) unless the agency is not meeting the state standards.

B. Consumer Support

1. Consumer Advocacy

Some RN supervisors and caseworkers interviewed described themselves as consumer advocates, but there is no formal advocacy system outside of TDHS and the agencies.

2. Consumer Training

No consumer training is offered except for basic health information from the RN supervisor if s/he considers it necessary.

3. Consumer Outreach

Program administrators consider outreach unnecessary, because the program has already become an entrenched part of the state service system. Vendors cannot actively recruit eligible clients through advertising campaigns, etc., instead they must rely on word-of-mouth recommendations from other consumers and caseworkers. Industry representatives and DHS administrators claim that the competition among vendors for client contracts improves overall service quality, because the program's reputation for quality are the only way to maintain a stable client base.

4. Quality Monitoring

The state has made administrative changes to clarify tasks among supervisory and gatekeeping personnel, solidify outcome monitoring procedures for provider agencies, and clarify client rights and client ability to chose. Over a two year period, a large manual was developed which defined the roles and relationships between the recipient, state attendant, case worker, agency nurse supervisor and state prior approval nurse.

The TDHS has also developed a compliance monitoring procedure for vendor agencies. The prior approval nurses are responsible for making sure that agencies maintain minimum standards of compliance in the following areas: referral response times, starting service times, continuity of services, reassessment procedures, determination of attendant competence, orientations of attendants with recipients, and explanations of complaint procedures to clients. Agencies must have a 90% compliance

rate, or their contract is canceled. On the first compliance reading, 15 % of agencies fail to meet standards, but almost all manage to improve by the next reading. Only one agency has in fact lost its PHC contract for consistent failure to meet standards, but word of the contract termination "spread like wildfire" among the agencies. Some advocates question the process, saying that the compliance standards are designed to assure consistency within the documentation, rather than improve the quality of the services for consumers.

VI. Attendant Issues: Family Providers, Wages, Benefits, Withholding

A. Family Provider Regulations

Currently the program excludes only spouses and legal or foster parents of minors, other family members can become paid providers. Parents of adult consumers providing PAS prior to program enrollment may be paid with Medicaid funds if the caseworker determines that the parent would otherwise be employed. One advocate notes sexism in this decision making process for some caseworkers: fathers may become paid providers but mothers are expected to provide PAS without reimbursement.

B. Attendant Wages

The state reimbursement per unit of service is \$6.96 per hour as of May, 1991, but attendant wages usually are at or near minimum wage. Agencies may give the attendant wages slightly higher than minimum wage if there is a labor shortage or under special circumstances, e.g. if the attendant is needed for a split shift (i.e. working only in the mornings and evenings). Some agencies in rural areas may offer attendants a small reimbursement for mileage, but most do not.

C. Attendant Benefits

The agency covers mandated benefits (FICA, social security, and unemployment).

D. Withholding and Liability Issues

Private agency representatives say that the state does not adequately recognize the added costs of potential liability for worker's compensation claims. Getting an increase in reimbursement in order to cover expanded attendant benefits and worker's compensation is a key issue on the industry's lobbying agenda.

VII. Program Context: The Relation of Medicaid Personal Care to the State Service Delivery System as a Whole

A. An Overview of Other State Programs

According to the Institute for Disability Access, roughly 20 programs in 5 state agencies (Department of Human Services, Rehabilitation Commission, Department of Mental Health and Mental Retardation, State Commission for the Blind, Department on Aging) are involved in some aspects of attendant service provision in Texas, and a full discussion of all these programs is clearly beyond the scope of this report. In terms of both expenditures and caseload, programs administered by the Texas Department of Human Services are the most significant.

Aside from Primary Home Care, the largest PAS program is the Family Care Program, a state-funded program which serves over 23,000 clients. This program is similar to Primary Home Care - contract agency providers are used, case-managers oversee many aspects of service delivery, and a maximum of 30 hours per week is provided. However, income eligibility is somewhat higher, no "medical need" must be demonstrated, and RN supervisors are not part of the service delivery system. Provider agencies compete for a DHS contract in a given region, rather than compete for individual clients like the open enrollment system of the PHC program.

The DHS administers the state-funded Client-Managed Attendant Care Program, which currently serves 350 clients on a sliding fee scale at a budget of \$2.6 million. Clients are responsible for hiring, firing, training and supervising their own attendant. Paramedical tasks delegated by a doctor can be provided. Clients can either receive a block payment for PAS (only one recipient has chosen this option), or may have a contract agency write the attendant's check and take care of necessary tax withholding. The contract agency also provides for a pool of attendants for emergency back-up.

The DHS also offers a small voucher program which gives individuals or their families up to \$300 per month for disability related needs including PAS. Limited sliding fee scale programs exist in certain areas which allow PAS provision on the job for working individuals. Shared attendant programs exist at 3 sites in order to provide more than 30 hours of PAS (recipients live in apartment complexes with at least one attendant on site at all times).

Medicaid waiver programs exist for children with disabilities, for people with mental retardation who would otherwise be institutionalized, and for people eligible for institutionalization, whose developmental disabilities are considered "related conditions", i.e. epilepsy, cerebral palsy, etc. The state is considering applying for waivers for people with AIDS/ARC, and for people who meet the medical criteria for nursing homes, i.e. they need daily observation or treatment by a nurse (e.g. people in a post acute hospital episode, or going through an acute episode in the community).

B. Who is Falling Through the Cracks?

Despite the number of programs existing in Texas, advocates identify many groups who are unserved or undeserved in their homes and communities. These include:

- People who cannot go for even one day without assistance or require more than 30 hours of service. Such individuals, if they do not have informal supports and other resources may remain in nursing homes and other institutions.
- People who have cognitive impairment or mental illness who do not have ADL deficits but need supervision.
- People who have family support may not receive paid PAS, even when informal service provision is causing social and economic distress for the family.
- People with head injuries which occurred after age 22, who need intensive supervision rather than direct ADL assistance.
- People or families may not know about the services available, e.g. undocumented workers.

C. The Political Future of the Personal Care Program

Primary Home Care will continue to be the largest component of the state's service delivery system. As the aging population grows and state funds become more limited, there will be pressure to direct more consumers to programs which access matching federal funds. The DHS recognizes several policy issues which will need to be addressed as the program develops.

Primary Home Care appears to have fulfilled its mandate to eliminate ICF Level II clients, but it has done this in part through a special waiver to cover the people who were income eligible for nursing home placement but whose income exceeded state levels for Medicaid eligibility outside an institution. The waiver will run out the summer of 1991, however most recipients will remain eligible for PHC because of a special clause in Section 4711 of OBRA 1990 that applies only to Texas.

The relationship between the state funded Family Care program and the Medicaid PHC program has come under some scrutiny. Both programs offer essentially the same service, i.e. PAS through agency providers. The differences between the program regulations have been questioned by both industry representatives and consumer advocates.

PHC serves people who meet strict income eligibility requirements, whereas Family Care has less strict income eligibility requirements. Because of federal regulation, agency RNs have become a critical part of the PHC program. The Family Care program, however, does not use RN supervisors (primarily because of cost considerations). Social workers involved in both programs say that for all practical purposes, consumers in the PHC and Family Care programs have the same conditions and are receiving the same services. Some advocates therefore question the high level

of RN involvement for all PHC recipients, saying that this may be unnecessary and intrusive, as well as costly. They suggest decreasing mandated RN supervision, in order to free up program expenditures for more services. The DHS administration does not believe that increased flexibility in RN supervision requirements would in fact lead to significant program savings.

Industry representatives argue that, given the reimbursement level for PHC, the DHS is getting "a tremendous bargain" in the RN supervisors. They suggest that RNs should be added to the Family Care program as well. The DHS administration says that it would like to add RN supervisors to the Family Care program, but believes the cost would be prohibitive.

The state is attempting to develop a solution to the service gap problem in PHC. A study is being conducted to identify the number of clients who are at risk if they are without services for even one day. The DHS administration is meeting with advocates and vendors, and plans to develop recommendations for the DHS board by August of 1991. The result may be that contract agencies will be required to provide dependable emergency services and more frequent supervisor visits for those at risk, and agencies will be reimbursed at a higher rate for these consumers.

The provision of paramedical services remains controversial. Disability activists are frustrated that program changes did not follow modification of regulations by the state Board of Nurse Examiners. The state feels it is bound by federal regulation as well as liability concerns from offering invasive medical procedures as part the PHC services, despite modification of state regulations. The issue appears to be stalemated at this point.

In general, DHS administrators demonstrate an understanding of and philosophical agreement with the goals of the independent living movement. The state appears committed to continuing dialogue and consensus with both advocates and vendors in the development of community based services.

Individuals Interviewed

Texas Department of Human Services

State Offices:

- Ernest McKenney, dir. of Services for the Aged and Disabled Community Care Programs
- Maria Montoya, Community Care Specialist
- Anita Anderson, Office on Disabilities

Austin Region:

- Carol Britton, CCAD Supervisor
- Karen Gonzalez, CCAD Supervisor
- Tom Lockett, CCAD Worker

- Karen Parshall, CCAD Worker
- Dorothy Hohlt, CCAD Worker
- Beverly Hamilton, CCAD Worker
- Judy Brunson, CCAD Worker
- Kathy Smith, Lead CCAD Nurse
- Helen Ward, CCAD Nurse
- Nancy Ivicic, CCAD Nurse

San Antonio Region:

- Ruth Gomez, Program Director
- Roy Jones, CCAD Supervisor
- Norma Cheeves, CCAD Supervisor
- Steve Blanchard, CCAD Supervisor
- Elsa Soliz, CCAD Worker
- Tony Rodriguez, CCAD Worker
- Katie Parker, CCAD Worker
- Josie Esquivel, CCAD Nurse
- Gloria Guajardo, CCAD Nurse
- Olga Gonzales, CCAD Nurse

Texas Association of Home Health Agencies:

- Anita Bradley, director
- Charles Gouge, Outreach Health Services
- Steve Mayberry, Concepts of Care

Concepts of Care, Austin Office:

- Kay Fangor, Program Director
- Marcia Montgomery, RN Supervisor
- Sharon Jones, Attendant

Medical Personnel Pool, San Antonio Office: - Roberta Bernhard, Director

- Mary Monroe, RN Supervisor
- Mary Helm, RN Supervisor
- Barbara Hall, RN Supervisor

United Cerebral Palsy:

- Patricia Anderson, director
- Joyce Dawidczyk, service coordinator

Coalition of Texans with Disabilities:

- Bob Kafka
- Stephanie Thomas

Grey Panthers:

- Charlotte Flynn, president

San Antonio Independent Living Services (SAILS):

- Larry Correau, Executive Director
- Willie Mae Clay, Advocacy Coordinator
- Mary Kay Sanders, IL Skills Training

San Antonio Consumer Coalition:

- Julio Hinojosa
- Angie Hinojosa
- Matt Kruger
- Troy Bielke
- Frank Childress
- Tanya Wade
- Kim Wong
- Laurie Andersen

APPENDIX A: QUESTIONNAIRES USED DURING SITE VISIT INTERVIEWS

Questionnaire for Administrators, Advisors and Advocates

I. Program History - Timeline

1. When was this program created?
2. What has been the evolution of services since that time? (probe for changes in regulations and requirements over time)
3. What groups and individuals pushed for the creation of this program and how did they impact the structure of this program (i.e. consumer groups, parent groups, providers, legislators, state/local government staff)?

II. Program Objectives and Population Served - Why was this program created?

1. What are the program objectives? (probe for: employment, community integration, deinstitutionalization) Are these objectives being met?
2. What population does this program target? (probe for: age, income, disability level, amount of informal support available) Is this population being adequately served?
3. Are there any plans to change the program's mission?

III. The Relationship of the PC-Option to Other State Services

1. How does this program compare to other PAS programs in the state? (probe for differences in populations served, i.e. age, income, severity of disability)
2. What is the relationship of this program to other PAS programs in the state? (probe for: referral relationship, fall back options, gap filling)
3. Who in the state still isn't being served in the home and community (probe for: those needing services 24 hours per day, cognitively disabled)?
4. What is the spectrum of Long Term Care Services in the state? (probe for: Who is targeted for each of these services?, What percentage of the total population served gets each of these services?, What percentage of total LTC expenditures go for each of these services?)

IV. Federal Oversight: To what degree has federal oversight impacted the design of this state's PC-Option program?

1. What are the current requirements of this program r.e. the following issues?:
 - a. medical supervision (probe for: by whom, how often, what does it entail - e.g. file review, home visit?)
 - b. location of service provision (probe for: limited to individual homes, board & care homes, medically related travel)

- c. family providers (probe for: definition of family, circumstances under which family provider is used)
 - d. Have any other Medicaid requirements shaped this program?
2. How would the following proposed HCFA regulation affect the program? (show summary card; probe for the impact on the population served and on the type and amount of services provided):
- a. Personal Care services are defined as "those tasks directed at the recipient and or his or her immediate environment that are medically related ... but would not include skilled services that may be performed only by a health professional."
 - b. Household and chore services can only be provided as directly related to personal care needs, and are not to constitute more than one third of the total time expended per visit.
 - c. Services can only be provided in the home or in connection with brief services outside the home for medical exam or treatment or shopping to meet health care or nutritional needs.
 - d. Exclusion of services for institutions serving more than four clients (e.g. board and care homes).
 - e. Exclusion of family providers, defined as: husband, wife, parent, child, sibling, adoptive child, adoptive parent, stepparent, stepchild, stepbrother, stepsister, father in law, mother in law, son in law, daughter in law, sister in law, brother in law, grandparents, grandchild.
 - f. Physician must review and reauthorize plan of treatment at least every six months. PC services must be specified in the plan of treatment to ensure that services are adequate and provided only to those who need them.
 - g. A registered nurse or "licensed practitioner of the healing arts" visit the consumer every three months to assess health status, need for PC services, quality of services, and to review plan of treatment.

V. Attendant Liability Issues - Who is the Employer?

- 1. Who is the attendant employer for purposes of tax liability (i.e. FICA, Income tax)?
- 2. Who is the employer for purposes of tort liability?
- 3. Who is the employer for purposes of worker's compensation and other labor related issues?
- 4. Is there program insurance for negligence?
- 5. How has concern about these liability issues impacted program design?

VI. Gatekeeping Functions: Eligibility Determination, Needs Assessment, Case-Management

- 1. Eligibility Determination
 - a. Who determines eligibility?
 - b. What does the process of eligibility determination entail and how much individual discretion is involved? (probe for formulas, guidelines)

2. Needs Assessment
 - a. Who provides needs assessment?
 - b. What does the process of needs assessment entail and how individualized is the service allocation? (probe for formulas, budget limits, individual discretion) Is there a per person cap on services or an average cap?
3. Case Management
 - a. Who provides case-management?
 - b. What are the minimum qualifications for case-managers?
 - c. What is the relationship of the case-manager to the program? (probe for: individual contractor, employee of provider agency, civil service employee)
 - d. What are the average caseloads?
 - e. Is there a mandated minimum level of case-management? (probe for flexibility based on need and capacity for self-management)
 - f. What is the scope of case management, i.e. do they assist in all the recipients needs or just Medicaid PAS?

VII. Support Services: Who Provides and Pays for the Following Services (i.e. State Government, County, City, AAA, ILC, Other Non-Profit, Consumer, Family, Friends, Other)?

1. Attendant Recruitment
2. Attendant Screening
3. Attendant Interviewing
4. Attendant Certification
5. Attendant Hiring
6. Attendant Training
7. Attendant Supervision
8. Attendant Payment
9. Attendant Termination
10. Consumer Advocacy
11. Consumer Training
12. Consumer Outreach
13. Conflict Resolution
14. Quality Monitoring

VIII. Relative Service Costs

1. What percentage of the overall program budget goes toward direct services (provider wages and benefits)?
2. What percentage of the overall program budget goes toward support services?
3. What percentage goes to case management?
4. What percentage goes to administration? (probe for definition of administration)

Medicaid Personal Care Option Site Visit Consumer Survey

1. Do you have problems getting attendants?
2. Do you have trouble keeping attendants?
3. Do you have a choice of attendants?
4. Are they types of attendant services you need available at the times you need them?
5. Do you have any backup system if there's an emergency?
6. Do you feel that attendants are adequately trained?
7. What do you do when you have a conflict with an attendant?
8. Do you feel comfortable in bringing problems with your services to the attention of program administrators?
9. Where do you get the following services (i.e. State Government, County, City, AAA, ILC, Other Non-Profit, Consumer, Family, Friends, Other), and who pays for them?
 - a. Attendant Recruitment
 - b. Attendant Screening
 - c. Attendant Interviewing
 - d. Attendant Certification
 - e. Attendant Hiring
 - f. Attendant Training
 - g. Attendant Supervision
 - h. Attendant Payment
 - i. Attendant Termination
 - j. Consumer Advocacy
 - k. Consumer Training
 - l. Consumer Outreach
 - m. Conflict Resolution
 - n. Quality Monitoring
10. Are there any other program strengths or weaknesses you think we should know about?

Medicaid Personal Care Option Site Visit Attendant Survey

1. What do you do in a typical work day?
2. What are your hours?

3. How much travel do you have to do? Do you get mileage reimbursement?
4. Are there any services that you are not allowed to provide to clients?
5. Do you feel that you were trained adequately for this job?
6. Do you feel the clients are getting adequate service?
7. Do you like your job?
8. Are you looking for other work?
9. What do you do when you have a conflict with a client?
10. Do you feel comfortable in bringing problems with your job to the attention of program administrators?
11. Are there any other program strengths or weaknesses you think we should know about?