WORLD
INSTITUTE
ON DISABILITY

1720 Oregon Street, Suite 4 • Berkeley, California 94703 • (415) 486-8314

June 13, 1984

Dear Lex,

On behalf of the Institute I would like to welcome you to membership in the Attendant Care Subcommittee of our National Advisory Committee. We are gratified by your willingness to join in the effort to make attendant care available to people who need it.

After long overstaying our welcome as a houseguest in our home of Associate Director Judy Heumann, the Institute recently moved into its own quarters at the above address. Early this year we received a grant from the Charles Stewart Mott Foundation to research several topics in the area of attendant care. As our first work product under this grant, we have completed a draft report on California's IHSS program. (This report was also done in response to a request from the Physically Handicapped Training Center at the University of Pennsylvania which is incorporating it into a larger study being done for the Pennsylvania Developmental Disabilities Planning Council).

A copy of this report is enclosed for your review and comment. We are planning to issue a final version for wider distribution this fall. Your suggestions for changes, deletions or additions are cordially invited. Any such suggestion should be sent by July 15th.

Hale Zukas, Kitty Cone and I are now working on the next phase of our attendant care project, a telephone survey of state officials and community service agencies in each of the states. We have also applied for an additional grant to study attendant care in more depth in a number of states. If we do gain the second grant (we have passed the first level of review and are awaiting final word),we will certainly have our work cut out for us for the next few years.

The institute is also growing in its other priority areas. Enclosed is a fact sheet that describes the range of our efforts.

Again, thank you for your willingness to become involved in our work; we look forward to working with you.

Sincerely,

Joan Leon

Joan Leon
Associate Director

JL:jm

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FACT SHEET

THE WORLD INSTITUTE ON DISABILITY (WID) - A public policy institute seeking solutions to the major problems faced by people with disabilities of all ages.

BACKGROUND AND PURPOSE: WID is a non-profit, 501 (c)(3) corporation focusing on major policy issues from the perspective of the disabled community. It was founded in 1983 by people who have been deeply involved in the development of the Independent Living Movement, the Center for Independent Living in Berkeley, California and other programs. If functions as a research center and as a source of information, training, public education and technical assistance. WID considers the following policy issues and activities as its priorities:

* an adequate attendant care system throughout the U.S. and internationally
* the continued development of independent living programs and services for elderly disabled individuals
* the continued support and development of the Independent Living Movement
* the utilization of the public media to enhance the general public's understanding of issues affecting disabled individuals
* training and consultation to public and private sectors to facilitate the integration of disabled people in the labor force and society
* facilitating a greater sharing of information and experiences in our primary areas of focus internationally

FOUNDERS AND STAFF: Edward V. Roberts, Director (Founder); Judith E. Heumann, Associate Director (Founder); Joan Leon, Associate Director (Founder); Anita Baldwin, Independent Living and Employment Specialist; Kitty Cone, Transportation and Attendant Care Specialist; Hale Zukas, Attendant Care and Architectural Barriers Specialist; Janet Macks, Administrative Assistant.

THE ORIGINS OF WID

The Bay Area is widely considered a major laboratory for the development of new approaches and solutions to the problems faced by disabled people of all ages. The Independent Living Movement of the disabled set down its roots in California in the 1960's and 70's when disabled people organized to gain passage of attendant care legislation and to develop the Center for Independent Living (CIL) in Berkeley, California. In the mid 70's Ed Roberts, the former Executive Director of CIL was named Director of the California Department of Rehabilitation. Under his leadership the Department of Rehabilitation stimulated the development of ILP's throughout California.

The State and the Bay Area have continued to be a major influence on program and policy development in such areas as: Transportation, education, health services, rehabilitation and employment. In the past ten years, especially since the formation of Disabled Peoples' International, a coalition of disabled people's organizations in more than 50 countries, the Bay Area and California as a whole has assumed an increasingly important role as a resource of information, model program development and technical assistance to other countries.

WID has chosen to use the Bay Area as a primary laboratory for its work because it is an area of the country that has, to an extraordinary degree, drawn people to it who are committed to working towards the amelioration of problems faced by a diverse population. The Bay Area has a wealth of community agencies providing direct services and advocacy, several main universities and community oriented foundations and corporations. These factors have led WID to conclude that many solutions to existing problems can be developed here. The Institute's goal is to assist in the development of these solutions and, while doing so, to disseminate the information and insight gained from the process to other areas of the country and internationally.

BOARD OF DIRECTORS: Dr. Philip Lee, Director of the Institute for Health Policy Studies, School of Medicine, University of California, San Francisco, and former Chancellor, University of California, San Francisco (Chairman); Robert Kerley, Vice Chancellor Emeritus, University of California, Berkeley; Dr. Jerome Tobis, Professor, Physical Medicine and Rehabilitation, University of California, Irvine; Dr. William K. Muir, Professor, Political Science, University of California, Berkeley; Edward V. Roberts, Director, WID, and former Director, California Department of Rehabilitation; Judith E. Heumann, Associate Director, WID, and former Senior Deputy Director, Center for Independent Living; Joan Leon, Associate Director, WID, and former Assistant Director, California Department of Rehabilitation (Secretary-Treasurer).

AFFILIATIONS: WID is a product of the Independent Living Movement of persons with disabilities and is closely allied with the National Council of Independent Living Programs, independent living programs throughout the country and other service and advocacy organizations of and for the disabled. It works closely with the Aging Health Policy Center, School of Nursing, University of California, San Francisco, and the Institute of Health Policy Studies, School of Medicine, University of California, San Francisco, and other academic and professional institutions.

WID PRIORITIES AND PROJECTS

ATTENDANT CARE: The availability of attendant care is an essential requirement of many disabled people. This service very often makes the critical difference in whether or not an individual can be employed or live in the community without the need for placement in nursing homes or other more costly restrictive environments. WID is studying the availability of attendant care around the country and will be proposing recommendations to strengthen this program. Attention is being given to other countries' approaches to the delivery of attendant care services.

Current projects: A survey of attendant care services in 50 states, a report on how the attendant care system functions in three California counties with an emphasis on mode of service delivery, and an in-depth study of attendant care services in five states (proposed).

AGING: More than 60% of the disabled population is 50 and older. Yet this group has benefited the least from the tremendous advances gained by the Independent Living Movement in the last two decades. WID is working to develop projects which will facilitate the transference of information and experiences gained by disabled people as a result of the Independent Living Movement to the elderly service system and elders who are experiencing disability.

Current projects: KPFA Radio interview show on disability and aging issues.

INDEPENDENT LIVING: The Institute is involved in the Independent Living Movement and is strongly supportive of the independent living programs (ILP's) developing in this country and around the world. WID is convinced that the ILPs' peer-support model is highly effective in promoting independence, self-reliance and greater social and economic involvement of disabled people in community life. WID is working with Bay Area ILP's, the National Council of Independent Living Programs, and other appropriate organizations on a range of issues including long term viability of ILP's, training and technical assistance needs.

MEDIA: Disability - the term evokes fear and pity. Yet millions of people are affected directly and indirectly by it every day. WID believes that the general public, disabled people and professionals in the fields of health care, disability, aging, education, housing, transportation, planning and social welfare need effective materials which explore issues and educate people on current issues and options. The Institute is working with people in the media industry on a number of issues and is creating and producing media materials which enable people to learn about important issues, i.e. attendant care, employment, independent living, health care and aging.

Current projects: A series of interview programs on KPFA Radio on a broad range of issues related to disability (Amnioscentisis, Aging and Disability, National Health Care and others).

EMPLOYMENT: Employment is a basic need that all people share. WID staff have worked with disabled individuals, legislators, government and employers to facilitate the hiring and employment of disabled individuals. The Institute is continuing to work with public and private employers who wish to insure that discriminatory policies and practices are removed and that disabled people are hired.

Current projects: The San Francisco City and County Department of Social Services has awarded WID a contract to provide consultation, technical assistance and training to improve the Department's capacity to successfully recruit, hire and employ disabled persons.

WORLD
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ON DISABILITY

DESCRIPTIVE ANALYSIS OF THE IN-HOME SUPPORTIVE SERVICES PROGRAM IN CALIFORNIA

Joan Leon
Hale Zukas
Kitty Cone

May, 1984

1720 Oregon Street, Suite 4 Berkeley, CA 94703 (415) 486-8314

a public policy center dedicated to the elimination of handicappism through the promotion of independence, equity of opportunity and full participation of people with disabilities

To the late Representative Phil Burton,
California, whose vision 20 years ago,
resulted in the establishment of the first
attendant care program in the United States

FORWARD

This report is one in a series of issue papers on the subject of attendant care, a major policy issue that the World Institute on Disability has taken on as one of its priorities over the next several years. Funding for the research and analysis that is the basis of these papers has come from the Charles Stewart Mott Foundation, the San Francisco Foundation, the Physically Handicapped Training Center (PHTC) of the Hospital of the University of Pennsylvania and other sources. In addition to the work of the principal investigators, Joan Leon (Associate Director, WID), Hale Zukas and Kitty Cone (Attendant Care and Transportation Specialists, WID), WID wishes to acknowledge the considerable contribution of Judith E. Heumann, WID Associate Director, and Janet Macks, WID Administrative Assistant, and to thank the many individuals in state government, independent living programs and consumers who responded to our telephone survey. We would like to especially thank Rick Kraft of the California Department of Social Services.

May, 1984

An Overview of the California In-Home Supportive Services Program

The California attendant care program (currently called In-Home Supportive Services or IHSS) is a 24-year old program funded through Title XX, state general funds, and a very small amount of county funds to provide assistance to those eligible aged, blind and disabled individuals who are unable to remain safely in their own homes without this assistance (IHSS Regulations). IHSS services include: domestic or cleaning services, meal preparation and laundry services; nonmedical personal care services, such as bowel and bladder care, bathing and grooming; paramedical services; removal of yard hazards; protective supervision, limited transportation services; and educational services to reduce the need for other supportive services (IHSS Regulations).

Those eligible for IHSS (subject to an individual determination of need) include the following:

a) persons who receive or are eligible for SSI.
b) persons who would be eligible for SSI except for excess income.
c) certain persons whose SSI has been terminated due to their employment.

Individuals in the latter two categories may have to pay a share of the cost of the IHSS they receive (IHSS Regulations).

The maximum amount allowed for attendant care is currently $872 per month for individuals who require at least 20 hours a week of the personal care services listed in section 12304(e) of the Welfare and Institutions Code, and $604 for those who need less.* These maximums apply statewide and cannot be exceeded.

IHSS recipients are predominantly elderly. According to preliminary data from a 1983 survey of IHSS program characteristics, the median age of recipients is 71. Of the total recipient population of 96,850, 13.9% are 85 or older, whereas only 1.2% are 21 or younger and another 8.3% are between the ages of 22 and 44 (Worchester).

According to the 1980 IHSS characteristics survey (most of the data from the 1983 survey has not been tabulated yet), 57.3% of the recipients are ambulatory, 33.1% are semi-ambulatory (needing assistance from another person or a device), and only 6.4% use wheelchairs.

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* This distinction, we might point out, is virtually meaningless, since it is highly unlikely that anyone requiring less than 20 hours a week of personal care services would nonetheless require more than $604 worth of services.

The proportion of recipients needing the various services listed in Section 30-757 of the IHSS Regulations is enumerated in the table shown in attachment #4. It is interesting to note that domestic services are provided to virtually all recipients, which is not surprising in a program that serves predominatly elderly persons. (See attachment #3).

In order to convey an adequate understanding of the California IHSS program, two of its fundamental aspects should be explained. First, to a greater extent than any similar program in the country, attendant care is treated as a social service, not as health or medically-related service. This orientation is apparent from the financial and administrative structure of the program. Approximately 58% of the program's estimated expenditures of 297 million dollars during fiscal year 1983-84 consists of federal funds coming entirely under Title XX; no Title XVIII or XIX funds are used. Responsibility for administration at the state level is lodged in the State Department of Social Services rather than the Department of Health Services. Since the program is decentralized to a large degree, the primary responsibility for its administration rests with each county's Welfare Department with most decisions being made by social workers, not health professionals.

By treating attendant care as an ongoing maintenance need, California has avoided the problems faced by other states when they have tried to shoehorn this nonmedical service into Title XIX, whose orientation is overwhelmingly medical. The California program thus embodies the independent living model much more than analogous programs in other states. Indeed, the existence of the California attendant care program was an important precondition to the birth and development of the Independent Living Movement.

Second, as we have mentioned above, the program is quite decentralized, county welfare departments being responsible for the actual delivery of services. In the late seventies, one of the authors of this report worked for three years to get the State Department of Social Services to develop and adopt a comprehensive set of regulations so there would be some statewide uniformity in the program. Eventhough the regulations have been in effect for several years, there is still considerable variation between counties. For example, a recent DSS study found "discrepancies among the counties in the assessment of need as well as in average hours" authorized for each service (Report on the Feasibility of Implementing Time per Task Standards in the IHSS program). As an illustration, attachment #2 shows the variation among selected counties in respect to the proportion of each county's IHSS caseload assessed as needing assistance with meal preparation and the average number of hours authorized for that service.

The Three Modes of Service Delivery: IP, Contract, County

In order to understand the variations in benefits, turnover rates and pay scale of attendants as well as the differences among clients served by the three modes, it is helpful to review how these modes differ from one another in practical operation. All counties are required to provide the IP mode (Individual Provider) for IHSS recipients; however, since this mode may not always fully meet the needs of all recipients, most counties also provide either the Contract or County mode. The following matrix shows a breakdown of the number of clients served by the different modes in California.

PERCENTAGE OF RECIPIENTS, HOURS AND EXPENDITURES
BY SERVICE DELIVERY MODE
JANUARY 1984

	Recipients	Hours	Expenditure
IP	77.3%	90.4%	83.4%
Contract	21.3%	9.3%	15.8%
County	1.4%	0.3%	0.8%
	100%	100%	100%

(taken from the IHSS Program Monthly Caseload, Hours and Costs Report for January 1984)

There is a marked difference between the populations served by the contract and county modes on the one hand and the IP mode on the other. At first glance it might seem that the contract and county modes are more cost effective than the IP, since the percentage of expenditures for each is less than the percentage of recipients. But the percentage of hours provided through each of the two modes is even lower. This indicates that the cases where the contract and county modes are used tend to be those needing the fewest hours.

Another area where counties have some autonomy is selection among three statutorily-permitted methods of providing IHSS: (1) paying individuals hired by the recipient (here after called the Individual Provider or IP mode), (2) contracting with an outside agency - whether a government unit, non-profit organization, or a profit-making firm - to provide the services (contract mode), or (3) using their own employees (county mode).

Since Section 12304 of the California Welfare and Institutions Code confers on severely impaired recipients* the right to hire and pay their own attendants, 57 of the State's 58 counties (one very small mountain county has no IHSS recipients) use the IP mode for at least part of their caseload; 28 counties use this method exclusively. Thirteen counties use county staff to provide services to part of their caseload. The remaining 16 counties contract with an outside agency after going through a bidding process; two profit-making corporations hold the contract in nine counties (IHSS Contract Mode Monthly Status Report).

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* For reasons which will be explained below, we regard the distinction between "severely" and "nonseverely impaired" as an artificial one which should not be legitimized by using these terms. Nonetheless we use them here purely for expediencies sake, it being much more unwieldy to use "persons who require at least (or less than) 20 hours a week of certain personal care services" instead of "severely or non-severely impaired".

It is also interesting to note that 63.7% of recipients having individual providers in 1980, received nonmedical personal services, whereas only 28.7% of those served by contract agencies and 18.7% of those served by county still received these services (IHSS April 1980 survey of selected characteristics).

There are several reasons for this "division of labor" among the three modes: one is the obvious consideration of cost; it is expensive to serve people who need a lot of attendant care through the contract and county modes.* Secondly, people who need only a few hours of help are likely to find it more difficult to find individual providers (mode study) and the tasks for which they need help are more likely to be amenable to tight scheduling. Finally, county and contract agency providers work only during normal working hours except in emergencies. Persons with only a few hours can obtain consistent service from the county and contract modes because the providers are scheduled to provide services to several individuals in the area and so are willing to do these smaller jobs. Providers are scheduled to substitute in case of an emergency.

Within all three modes, the initial procedure is the same. The potential recipient is visited by a county social worker who makes an assessment of the individual's needs and whether or not there is someone who can meet those needs at no cost. The social worker also determines whether the recipient is capable of handling his/her own attendant, including recruitment, hiring and firing, management and training.

A needs assessment form (attachment #1) is used to determine the service needs of the individual and to compute the allowable hours of service. The various modes of service delivery available in the county are discussed and a decision is made. Eventhough all clients may be served by the IP mode, many who need less than 20 hours a week choose the county or contract mode because of the difficulties involved in managing one's own attendant. However, almost all individuals who require 20 hours or more choose the IP mode because it alone offers the number and flexibility of hours and personal choice that many people need and desire.

The IP Mode

a) Attendant Management

Under the IP mode, an important concern is the ability of the recipient to manage their own attendant care. A social worker may refer an individual to an agency such as an independent living

*This is only one of several ways through which fiscal considerations shape the program.

program for attendant management training or may send a county worker to the home to assist the recipient initially in organizing an attendant care routine (Keller).

b) Finding an attendant

The social worker is required to make "reasonable efforts" to help an individual find an attendant care provider (IHSS Regulations). This usually involves asking the recipient if he/she knows of persons who can fill the need. Many recipients already have someone in mind, a relative, friend or neighbor (more than half of individual providers fall into one of these groups). If the client has no one in mind, the social worker who is required to make "reasonable efforts" to help a client find an attendant suggests how to locate an attendant or may refer applicants. Most counties maintain a list of available attendants compiled from referrals from the State Employment Development Department (schools, churches and service agencies), classified ads and public service announcements. There is no "system" for attendant referral and it varies considerably from county to county.

The recipient is then essentially on his/her own. The recipient and the attendant work out their own schedule and the social worker only becomes involved when there is some difficulty or some need for a reassessment of hours. Each recipient in the IP mode sends a timesheet for each provider, which they both sign, to the county social services department once or twice a month. For the 93% of IP recipients who do not handle payment of their attendants themselves (1980 DSS Survey) this data is sent to EDS-Federal (the payrolling agent used by the program), which then issues checks to the providers. For the remaining 7% who receive advance payment, the timesheets serve mainly as an auditing mechanism to insure accountability.

c) Attendant profile

The majority of attendants are family members, friends or neighbors. The IHSS system is quite precise in the delineation of the circumstances in which a family member may be paid to provide attendant care services (IHSS regulations Section 30-763).

Over the years, the regulations governing the circumstances under which spouses and parents of minors can be paid as providers have loosened and tightened. Generally speaking, a spouse or parent may receive payment for attendant care services if the provision of those services forces the person to leave or not enter full-time employment. Those services, considered a part of

the normal parental or spousal obligation, are not paid. In 1983, the regulations were liberalized to allow a family member to receive payment for accompanying a recipient on a health-related trip and for providing protective supervision (Section 12301 of the Welfare and Institutions Code). There is relatively little information available about who attendants are other than that which is reported in the DSS 1980 Survey of Selected Characteristics and the informal comments of social workers, attendant referral counselors working in independent living programs, and recipients. The typical attendant is an older woman who is a former homemaker. The 1980 DSS study found that 1.7% were aged 21-29, 14.2% age 30-39, 18.2% age 40-49, 16.9% age 50-59 and 7.5% age 60-64). In addition to displaced homemakers, attendants are often students, people who prefer to work as care givers, and those who prefer working hours other than 9 to 5.

d) Consumer satisfaction and attendant turnover

As part of its 1983 IHSS Evaluation, DSS conducted surveys of consumer satisfaction and attendant turnover. Both surveys present a picture of a generally stable system, with a fairly high level of client satisfaction.

DSS found a high level of satisfaction (97%) with provider's performance, reliability, attitudes, etc. under the IP mode. Satisfaction was slightly less under the contract (95%) and county (88%) modes. (One of the major reasons for the difference is that providers under the county and contract modes work fewer hours and are sometimes unable to complete certain duties within the allotted time - e.g. defrosting a refrigerator). Limited weight, however, should be given to these results since the data may reflect a common reluctance to complain about a care giver and a recipient's lack of comparative basis on which to assess the quality of care received.

The 1983 IHSS Evaluation found the level of turnover with IP providers surprisingly low and where a client experienced high turnover this was frequently caused by the recipient's problems with attendant management.*

According to Mary James, the DSS Analysist who carried out the field interviews for the 1983 Evaluation, some recipients, particularly elderly women had never had experience dealing with an employee, did not realize that they were the employer since they didn't pay the provider directly. When problems arose, they tended to refer the problems to the social worker.

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*The DSS 1980 study shows that 59.4% have been receiving IHSS services less than a year and therefore could be considered inexperienced in attendant care management.

The Independent Living Programs reported a fairly high turnover. The different reports can be attributed to the fact that the ILP counselors are only seeing clients when they need a provider and that the turnover of non-family providers is much greater than family.

e) Attendant wages

Each county sets the hourly wage it allows for attendants. Many counties still only allow the minimum wage of $3.35 per hour.(Kraft). In 1983-1984, approximately $7,000,000 was appropriated in the State Budget for an optional 3% cost of living adjustment for attendants in the IHSS system. Twenty two counties have exercised this option so their allowable wage is at least $3.45 an hour (Analysis of the Budget Bill). A very few counties allow slightly more; the highest we have found is $3.71 an hour in San Franciso (Keller). The only benefits attendants receive under the IP mode are the mandatory deductions for social security, workers' compensation and unemployment insurance.

Because IHSS does not cover vacation, sick leave and other benefits for IP providers, recipients often feel that they must make special arrangements with their providers (e.g. allowing time off that is not reported to DSS) in order to keep a good employee who might otherwise find a better paying job.

f) Attendant Referral through Independent Living Programs

There are 22 independent living programs in California. These consumer based and operated programs help people with problems of IHSS eligibility and all aspects of attendant recruitment, screening, training referral and management. The attendant referral counselors also often provide assistance with problems that arise (i.e. attendant burnout, high turnover, communication problems, etc.).

Of the attendant referral counselors interviewed by WID, all but one indicated that they obtained referrals through newspaper ads, public service messages, college and school employment offices, fliers, the EDD, churches and other organizations. The Center for Independent Living in Berkeley indicated that a sufficient number of attendants were walking in their doors as a result of informal word of mouth contact. Independent living programs do not charge a fee for their services.

Individuals seeking work as an attendant are screened and interviewed to determine levels of experience, possible attitudinal problems and the type of work desired. Inexperienced persons are given an explanation of what might be required of them in personal care work. (see section on training)

The ILP's are open Monday through Friday from 9:00-5:00. Most of the attendant referral services maintain a list of emergency attendants who are "on call" for specific dates and times.

g) Rural and Urban differences

The Department of Social Services has not looked into the possible differences in attendant care delivery in rural and urban areas. In our informal survey of county officials, independent living programs and consumers, we have concluded that the differences that exist are slight and seem to be more closely related to the economic conditions in the area than other factors. Eventhough rural areas tend not to have the range of service agencies found in a major city, they do have active charitable and social organizations (churches, fraternal organizations, etc.). In addition their population is probably more homogeneous, more stable and less transient than in urban areas. For example, in Kern County, which is the size of Massachusetts and much of which is very sparsley populated, there are waiting lists of people wanting to be attendants (Baird).

The Contract Mode

In California, 15.4% of the recipients are served through the contract mode and 16 counties use a combination of contract and IP modes.

Counties which contract with outside (home health) agencies do so on the basis of the lowest hourly cost bid. Of the 16 contracts currently in effect, the hourly cost ranges from $4.83 to $8.52 per hour with an average of $7.18. This figure includes agency administrative cost, profit and provider wages.

For example, in San Diego, Upjohn has contracted to provide service for $6.30 per hour. There are three provider classifications - each having several wage levels ranging from $3.61 at entry level to $4.84 for the most skilled provider at the top step (Chavez). Similarly, San Francisco has a contract with Remedy Home Health Inc. to provide services at a rate of $7.90 hour. Remedy's wage rates range from $4.20 for an entry level position to $6.15 per hour after nine years of employment (Keller).

In addition to the mandatory benefits, agency providers receive vacation and sick leave as well as health insurance, the cost of which is usually shared.

Contract providers generally serve people needing a small number of hours per month and rarely serve the severely impaired. Because of the statutory limit of $872 per month, persons requiring a large number of hours cannot be served by contract providers unless a special rate is negotiated.

The County Mode

The county mode serves only 1.4% of the state's IHSS recipients and is utilized in 13 counties. The providers are hired under the civil service classification of Homemakers and most earn a higher rate of pay and receive more benefits than providers in the IP and contract mode. This may partially account for the higher morale and low turnover; some homemakers have been employed by county welfare departments for 20 years (Kern County is an example).

The hourly cost for county providers ranges from $5.47 (Shasta County) to $12.56 (Glenn County) with an average of $9.54 (DSS Monthly Caseload, Hours and Costs, January 1984). The largest county-run program in the State is in Kern County where 382 clients (out of a total IHSS caseload of 1138) are served at a cost of $11.99 per hour. Provider wages range from $5.20 an hour for a Homemaker I (trainee) to $7.45 for a Homemaker III.

The county mode is thus the most expensive in terms of costs per hour but the counties that utilize this mode tend to feel that it is cost effective because of the tighter supervision possible over the providers' job performance and the recipients' hours (Baird).

The Performance of Paramedical Services

A critically important aspect of the California program is the provision of personal care services to severely impaired individuals by attendants who are not licensed and have not received medical training.

These non-medical personal care services for which there is no supervision required, include:

a) Bowel and bladder care, such as assistance with enemas, emptying of catheter or ostomy bags, assistance with bed pans, application of diapers, changing rubber sheets and assistance with getting on and off commode or toilet.

b) Respiration limited to nonmedical services such as assistance with self-administration of oxygen and cleaning IPPB machines.

c) Consumption of food consisting of feeding or related assistance to recipients who cannot feed themselves or who require assistance with special devices in order to feed themselves.

d) Routine bed baths

e) Bathing, oral hygine and grooming

f) Dressing

g) Rubbing of skin to promote circulation, turning in bed and other types of repositioning, assistance on and off seats and wheelchairs, or into and out of vehicles.

h) Moving into and out of bed

i) Care of and assistance with prosthetic devices

j) Routine menstrual care, limited to application of sanitary napkins and external cleaning

k) Ambulation, consisting of assisting the recipient with walking or moving the recipient from place to place. (IHSS Regulation 30-757)

There is another less easily defined category now termed paramedical services, which includes menstrual or bowel and bladder care which requires the insertion of any object (tampon, catheter, finger) into the body or the puncturing of the skin. These services had always been provided by attendants since the inception of the California attendant care program in 1960.

In 1979, however, the state issued a directive that these services would no longer be provided under IHSS. This directive came out of the clear blue sky, since to our knowledge there had been no untoward consequences arising from the inclusion of these services in the program for 19 years.

Some have speculated that the directive was issued as a device to get some people off of IHSS and into nursing homes. This would have saved the state money, since any savings in the IHSS program consisted entirely of state dollars (the federal share of the program being a fixed amount each year), while the state pays less than half the cost of nursing home care, the rest being borne by the federal government under Title XIX.

This directive predictably set many disabled consumers and organizations into an uproar, and state legislation was quickly enacted which provided that paramedical services are to be provided under IHSS.

Under the new IHSS regulations (30-757), certain services which previously were delivered without being "under the direction of a licensed health care professional" are now defined as paramedical.

Paramedical services are:

1) The services shall have the following characteristics;
   a) are activities which persons would normally perform for themselves but for their functional limitations,
   b) are activities which, due to the recipient's physical or medical condition, are necessary to maintain the recipient's health.
2) The services shall be provided when ordered by a licensed health care professional who is lawfully authorized to do so. The licensed health care professional shall be selected by the recipient. The recipient may select a licensed health care professional who is not a Medi-Cal provider, but in that event shall be responsible for any fee payments required by the professional.
3) The services shall be provided under the direction of the licensed health care professional.
4) The licensed health care professional shall indicate to social services staff the time necessary to perform the ordered services.
5) This service shall be provided by persons who ordinarily provide IHSS. The hourly rate of provider compensation shall be the same as that paid to other IHSS providers in the county for the delivery method used.

The number of persons receiving paramedical services statewide is reported as 854. It is widely believed that the number of people receiving these services, but not reporting them as paramedical, is much higher. It is perceived as an inconvenience to find a doctor willing to take responsibility for this supervision. Since some of these services are very similar to non-paramedical personal care services for bowel and bladder, menstrual care,

etc., they can be assessed for time purposes, as their similar personal care services at the time of the assessment to avoid the supervision requirement. In addition, for the same reason, some disabled persons requiring these services simply do not have them assessed and have them performed by their attendants anyway. We have been told by DSS personnel that the requirement is so unrealistic that many recipients have an informal understanding between their social worker, the attendant and themselves on this issue.

According to Rick Kraft, DSS Analyst, there has never been any legal action taken as the result of the provision of para-medical services in the 24 year history of the program. We assume there are several reasons for this. First, if a client shows indications during the initial interview and assessment that he/she is incapable of managing personal care services in general, the role of the social worker is to then make certain that sufficient training occurs or that the person is assigned providers who can take responsibility.

A more general reason seems to be that most self-directed disabled individuals have had sufficient experience with their own personal care prior to coming into the program, to be well equiped to train and supervise their own attendants. They have learned who these services are to be performed from their prior care-givers-parents, other family members, etc., or have developed their own ways of dealing with their condition.

In summary, under IHSS, unlicensed non-medically trained attendants have been successfully providing personal care services to disabled recipients for 24 years with no documented legal complaints at a very low cost to the taxpayer.

It is worthy of note that the fact that these services are being provided by people having no <u>formal</u> training is accepted with complete equanimity. (That this practice has had no negative consequences, legal or otherwise, no doubt has alot to do with this attitude.) Quite correctly, they feel that a little common sense and sensitivity is more important to performing these tasks correctly than having sat through a class for a certain number of hours. As one person in the State Department of Social Services commented, "It really is a matter of common sense."

Training

There seems to have been very little formal training available to either recipients or providers in the California experience. The vast majority of the providers apparently rely on the recipient for whatever instruction is necessary.

The 1980 DSS Characteristics Study indicates that virtually all of the county providers and about two-thirds of the contract providers received some training and that almost 75% of the individual providers received no formal training. The sources of this training include community colleges, hospitals, county and contractor training sessions and, in recent years, independent living programs. The training offered by the independent living programs tends to focus on the concept of attendant care more than its practice. These programs explain what the tasks involved in attendant care are rather than how to do them; the more practical training is left to the disabled individual who employs the attendant. As the attendant referral counselor at the San Francisco Independent Living Project put it, "We are the high school and the disabled person is the college."

In addition, several independent living programs are now offering effectiveness training for disabled persons who need help with attendant management. In many cases, the disabled people who take part in this training have lived in an institution or in the care of their families and have not had experience with living independently and managing their own attendant care needs. The training focuses on time and money management, assertiveness and other skills that are critical to an independent lifestyle.

An example of this type of training is a new program offered by the Center for Independent Living in Berkeley. Over a six week period, a maximum of ten disabled people will meet once a week and study the following topics:

* Assertiveness Training
* Selection and interviewing procedures including identification of specific needs, compatability, identification of skills in prospective attendant.
* Definition of rights and responsibilities of client and attendant
* Hiring procedures
* Defining duties - "being clear" "communication skills"
* Training attendant
* Time management
* Money management
* Record keeping

* Paying an attendant
* Evaluation procedures
* How to deal with: grievances; theft; firing attendant
* Job incentives to keep good attendants

In addition the trainees are encouraged to form a peer support group which can meet on an ongoing basis to deal with management problems as they arise (Walker).

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ATTACHMENT #1

IN HOME SUPPORTIVE SERVICES NEEDS ASSESSMENT

☐ New Assessment ☐ Changes
☐ Periodic Assessment

NAME	AGE	DATE HV	GOAL #	CASE NUMBER

LIVING ARRANGEMENT

☐ House ☐ Apartment ☐ Mobile Home ☐ Hotel ☐ Other

No. of rooms

Laundry facilities ☐ YES ☐ NO
Cooking ☐ YES ☐ NO

OTHER PERSONS IN HOUSEHOLD	AGE	RELATIONSHIP	Rec. IHSS Yes	Rec. IHSS No	ABILITY TO ASSIST

EMERGENCY CONTACT	PHONE

ASSESSMENT

PHYSICIAN

Is client able to supervise provider and give directions for household and personal care needs? ☐ YES ☐ NO If NO, who will supervise provider?

DIAGNOSIS AND PROGNOSIS:

CLIENT'S AND/OR SOCIAL WORKER'S DESCRIPTION OF FUNCTIONING:

CLIENT'S FUNCTIONING: (circle the appropriate number according to assessment guidelines)

Mobility Inside	1 2 3 4 5	Meal Preparation	1 2 3 4 5	Grooming	1 2 3 4 5
Light Housework	1 2 3 4 5	Eating	1 2 3 4 5	Transfer	1 2 3 4 5
Laundry	1 2 3 4 5	Bathing	1 2 3 4 5	Bowel & Bladder	1 2 3 4 5
Shopping	1 2 3 4 5	Dressing	1 2 3 4 5	Special Functions	1 2 5

SERVICES	SERVICES NEEDED	SERVICES AWARDED	SERVICES	SERVICES NEEDED	SERVICES AWARDED
1. Cleaning			*12. Ambulation		
2. Laundry			*13. Moving into and out of bed		
3. Shopping			14. Bathing, oral hygiene and grooming		
4. Meal clean up and menus			15. Rubbing skin, etc.		
*5. Preparation of meals			16. Care and assistance with prosthesis		
*6. Respiration			17. Transportation services (accompany)		
*7. Bowel and bladder care			a. Medical appointment		
*8. Feeding			b. To alternative resources		
*9. Routine bed baths			18. Yard hazard abatement		
*10. Dressing			19. Non-medical protective supervision		
*11. Menstrual care			20. Teaching and demonstration		

COMMENTS

Severely impaired? ☐ YES ☐ NO If yes, total hours weekly needed of starred items:

Is Heavy cleaning needed more than once per year? ☐ YES ☐ NO If yes, justify per MPP (30-457.22 or .23)

Was heavy cleaning provided during the last authorized period? ☐ YES ☐ NO

Should heavy cleaning be provided during the current authorized period? ☐ YES ☐ NO

ALTERNATE RESOURCES

SOURCE	SERVICE

Number of days provider works: _____

RECOMMENDED AWARD (Weekly)

	Other Help (check) None	Some	Most	Predicted Hours	IHSS Hours
Domestic (Services 1-3)					
Meals (Services 4-5)					
Non-Medical Personal (Services 6-16)					
Other (Services 17-20, circle below) 17a 17b 18 19 20					
TOTAL WEEKLY HOURS:					

Was a comment asked for to explain a significant difference between the award and prediction? ☐ YES ☐ NO
If YES, what factor best explains that difference:
☐ fair hearing decision ☐ client independence ☐ flat-rate case
☐ other: _____

APPROVAL

A. ☐ EMERGENCY - 2 wk. maximum From _____ To _____

B. ONGOING: Hrs. approved _____/wk _____/mo From _____ To _____

SWS APPROVAL

SOCIAL WORKER DATE	PHSW DATE	SUPERVISOR DATE	MSRT COORDINATOR DATE

Comments: _____

ASSESSMENT GUIDELINES

Rate the client's actual functioning level, independent of any help which they may be receiving in a particular category. The client's functioning score should reflect physical, mental/emotional, or environmental limitations.

MOBILITY INSIDE

1. is independently mobile (may experience accompanying pain)
2. requires assistive device (cane, walker) or uses furniture for support. Requires no physical assistance or supervision
3. requires mechanical device (wheelchair) but not physical assistance or supervision
4. requires some physical assistance or supervision
5. requires total assistance or bed bound

LIGHT HOUSEWORK (dishes, dusting, dust mopping, straightening bed, putting away groceries)

1. can do all applicable chores without difficulty
2. experiences continuing or intermittent difficulty with some chores; can generally perform all chores
3. cannot perform *some* chores
4. cannot perform *most* chores
5. cannot perform *all* chores

LAUNDRY (heavy wash, light wash, hand wash, routine mending, ironing, folding clothes)

1. can perform all applicable chores
4. has difficulty with most/all chores; can perform one or more chores
5. cannot perform any of the chores

SHOPPING (weekly groceries, supplemental food items, other shopping errands)

1. can perform *all* the shopping tasks without assistance
3. can perform *some* shopping tasks without assistance
5. cannot perform any shopping tasks

MEAL PREPARATION

1. can do all meal preparation with adequate nutrition
2. can do most cooking with assistance in planning/supervising diet and/or assistance with meal clean-up
3. can prepare light meals
4. can prepare only light snack food
5. cannot prepare any meals

EATING

1. can feed self without difficulty
2. can feed self but with accompanying difficulty/pain
3. can feed self with supervision (e.g., verbal encouragement, diet planning)
4. can feed self if food is specially prepared (e.g., cut up, pureed)
5. cannot feed self without physical assistance

BATHING

1. can bathe self without assistance
2. can bathe self with general supervision
3. can bathe self with assistance in getting in/out of tub
4. cannot bathe self in tub without physical assistance
5. must be bed bathed

DRESSING

1. can dress self without difficulty
2. can usually dress self but with accompanying difficulty/pain
3. cannot put on some garments without assistance (e.g., those having zippers and other fasteners; socks, hose, etc.)
4. cannot put on most clothing items
5. cannot dress self at all

GROOMING (hair combing, shampooing, oral hygiene, shaving)

1. can do all chores without difficulty
2. experiences continuing or intermittent difficulty with some chores; can generally perform all chores
3. cannot perform *some* chores
4. cannot perform *most* chores
5. cannot perform *all* chores

TRANSFER

1. can transfer without difficulty
2. can transfer with accompanying difficulty/pain
3. can transfer with assistive devices (e.g., hand bars or overhead bars)
4. cannot transfer without some physical assistance or supervision
5. cannot transfer unless lifted and physically moved (hoyer lifts,etc.)

BOWEL AND BLADDER FUNCTIONING

1. no difficulty/no assistive devices used
2. uses bathroom with assistance to/from or on/off toilet (including the use of assistive devices)
3. uses bedside commode, bed pan, or indwelling catheter with assistance
4. is incontinent in bladder functioning (on an intermittent or on-going basis) but does not use catheter
5. is incontinent in bowel functioning on an intermittent or on-going basis

SPECIAL FUNCTIONING (menstrual care, respiration, ambulation)

1. not applicable or no difficulty
5. requires assistance in one or more areas

ATTACHMENT #2

STATE OF CALIFORNIA — HEALTH AND WELFARE AGE

DEPARTMENT OF SOCIAL SERVICES

REQUEST FOR ORDER AND CONSENT — PARAMEDICAL SERVICES

PATIENT'S NAME
MEDI-CAL IDENTIFICATION NUMBER

TO:

Dear Doctor:

This patient has applied for In-Home Supportive Services (IHSS) and stated that he/she needs certain paramedical services in order for him/her to remain at home. You are asked to indicate on this form what specific services are needed and what specific condition necessitates the services.

In-Home Supportive Services is authorized to fund the provision of paramedical services, if you order them for this patient. For the purposes of this program, paramedical services are activities which, due to the recipient's physical or mental condition, are necessary to maintain the recipient's health and which the recipient would perform for himself/herself were he/she not functionally impaired. These services will be provided by In-Home Supportive Services providers who are not licensed to practice a health care profession and will rarely be trained in the provision of health care services. Should you order services, you will be responsible for directing the provision of the paramedical services.

Your examination of this patient is reimbursable through Medi-Cal as an office visit.

If you have any questions, please contact me.

SIGNED	TITLE	TELEPHONE NUMBER	DATE

TO BE COMPLETED BY LICENSED PROFESSIONAL

NAME OF LICENSED PROFESSIONAL	OFFICE TELEPHONE

OFFICE ADDRESS (IF NOT LISTED ABOVE)

TYPE OF PRACTICE

☐ Physican/Surgeon ☐ Chiropractor

☐ Podiatrist ☐ Dentist

CONTINUED ON BACK

RETURN TO: (County Welfare Department)

Does the patient have a medical condition which results in a need for IHSS paramedical services?:

☐ YES ☐ NO If YES, list the condition(s) below:

List the paramedical services which are needed and should be provided by IHSS in your professional judgement.

TYPE OF SERVICE	TIME REQUIRED TO PERFORM THE SERVICE EACH TIME PERFORMED	FREQUENCY *		HOW LONG SHOULD THIS SERVICE BE PROVIDED?
		# OF TIMES	TIME PERIOD	

* Indicate the number of times a service should be provided for a specific time period: (Example: two times daily, etc.)

Additional comments:

☐ IF CONTINUED ON ANOTHER SHEET, CHECK HERE

CERTIFICATION

I certify that I am licensed to practice in the State of California as specified above and that this order falls within the scope of my practice. In my judgement the services which I have ordered are necessary to maintain the recipient's health and could be performed by the recipient for himself/herself were he/she not functionally impaired.

I shall provide such direction as is needed, in my judgement, in the provision of the ordered services.

I have informed the recipient of the risks associated with the provision of the ordered services by his/her IHSS provider.

SIGNATURE ▶ DATE

PATIENT'S INFORMED CONSENT

I have been advised of risks associated with provision of the services listed above and consent to provision of these services by my In-Home Supportive Services provider.

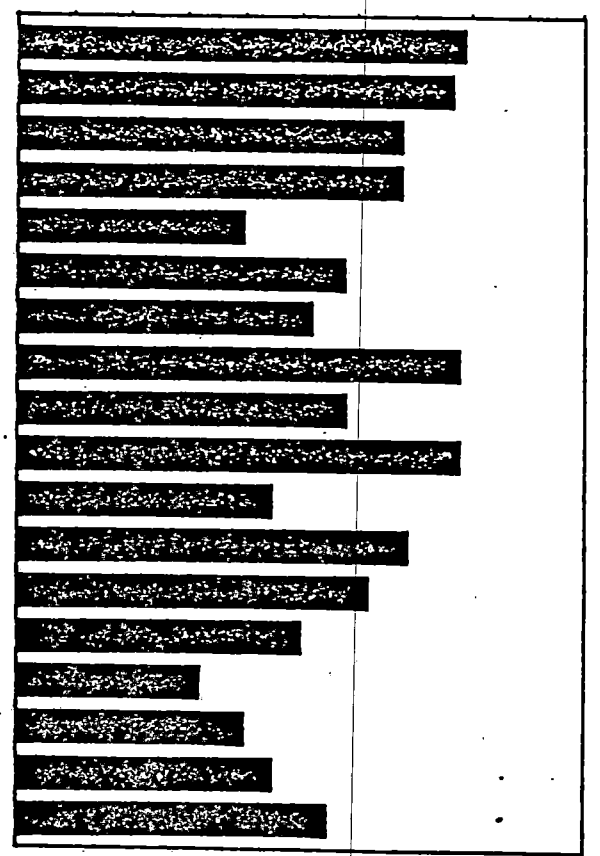
SIGNATURE ▶ DATE

ATTACHMENT #3

Average hours and utilization rates for meal preparation in 18 large counties are compared in the following chart:

RECIPIENTS ASSESSED MEAL PREPARATION BY COUNTY WITH AVERAGE WEEKLY HOURS

COUNTY	AVERAGE WEEKLY HOURS	PERCENT
LOS ANGELES	6.40	79%
SAN FRANCISCO	5.43	77%
SAN DIEGO	5.64	68%
ORANGE	3.40	68%
SAN BERNARDINO	6.04	40%
SANTA CLARA	8.31	58%
FRESNO	9.17	52%
CONTRA COSTA	8.35	78%
RIVERSIDE	3.81	58%
SACRAMENTO	5.73	78%
TULARE	6.72	45%
SAN MATEO	5.00	69%
SONOMA	10.41	62%
KERN	4.43	50%
STANISLAUS	5.85	32%
SAN JOAQUIN	4.14	40%
SANTA BARBARA	6.00	45%
SANTA CRUZ	9.64	55%



IHSS 5/82

ATTACHMENT #4

Table 26

IN-HOME SUPPORTIVE SERVICES

TOTAL ASSESSED RECIPIENT NEED[1/] AND AVERAGE WEEKLY HOURS OF ASSESSED NEED, BY TYPE OF SERVICE

April 1980

Services	Recipients		Average weekly hours
	Number	Percent	
TOTAL	97,579 [2/]	100.0 [2/]	16.5
Domestic services	94,554	96.9	2.7
Related services	80,795	82.8	7.8
Nonmedical personal services	53,864	55.2	9.1
Transportation services	36,787	37.7	1.7
Yard hazard abatement	2,049	2.1	1.5
Protective supervision	6,831	7.0	23.4
Teaching and demonstration	293	0.3	2.2
Paramedical services	976	1.0	4.6
Other	98	0.1	---

1/ Total need refers to the hours of service per week the recipient needs (not receives) to live safely in his own home.

2/ Because recipients can receive more than one type of service, item numbers and percentages of recipients receiving services do not add to item totals.