The Many Faces of Consumer-Direction: Consumer Co-ops for People with Disabilities who use Personal Assistance Services

Lessons Learned from a Failed Project: A Post-Mortem Analysis of the California PAS Consumer Co-op Project

This project was
Funded by the Robert Wood Johnson Foundation
Independent Choices Program
Grant #32150

and, in part,
by the Administration on
Developmental Disabilities
Grant #90DD0486

The opinions expressed in this report are those of
the authors and do not necessarily reflect the views of
The Robert Wood Johnson Foundation
or the Administration on Developmental Disabilities

For more information about this report, contact Barbara Wheeler, Ph. D.
(323) 671-3829 • bwheeler@chla.usc.edu
The Many Faces of Consumer-Direction: Consumer Co-ops for People with Disabilities who use Personal Assistance Services

Lessons Learned from a Failed Project: A Post-Mortem Analysis of the California PAS Consumer Co-op Project


Barbara Wheeler, Ph.D.
University of Southern California
University Affiliated Program & Keck School of Medicine

Eldon Luce¹
In-Home Supportive Services Consultant

E. Kim Coontz²
Center for Cooperatives
University of California, Davis

Graphics and Layout Design by:
Mike Kritzer
effective Designs
www.effectiveWeb.f2s.com

¹During the course of this 3-year project, Mr. Luce was Executive Director of the San Mateo Public Authority, then an independent consultant in IHSS, and is currently Executive Director of the Contra Costa Public Authority
²Ms. Coontz was the Co-op consultant to this project. Our appreciation to the Center for Cooperatives at UC Davis, which provided her time in-kind.
In 1997, the USC University Affiliated Program was awarded a 3-year grant from the Robert Wood Johnson Independent Choices Program to establish four consumer cooperatives for people who use personal assistance services\(^3\) in California. It was anticipated that consumer co-ops would be an effective model for promoting consumer direction for people who relied on other people to conduct routine activities of daily living—a model which would go beyond current models of consumer-direction for this population in California. It should be noted that all data cited in this report are referenced to the project period, 1997-2000.

\(^3\) A broadly inclusive term which refers to any form of assistance with a task that a person would normally do for himself if s/he did not have a disability (Litvak et. al., 1991). Such tasks include activities of daily living (ADL’s) such as bathing, dressing, eating, toileting, etc.) and instrumental activities of daily living such as housecleaning, shopping, meal preparation, balancing a checkbook, etc. This delivery of this set of services becomes a forum for the successful exercise of autonomy and control as personally defined by the recipient of service.
Who Needs A Co-op?
I. **INTRODUCTION**

A. Why a Cooperative?
B. What is the Relationship between Co-operatives and the RWJF Independent Choices Program?

II. **WHY A CO-OP FOR IHSS RECIPIENTS?**

A. California's IHSS Program
   1. IHSS Residual Program & Personal Care Services Program (PCSP)
   2. Modes of IHSS Service Delivery
      a. County Homemaker/Chore Mode
      b. Contract Mode
      c. Independent Provider (IP) Mode (Intermediary Service Organizations)
      d. Mixed Modes
   3. Enhancements to the IP Mode--Intermediary Service Organizations
      a. Supported Independent Provider (SIP).
      b. Public Authority: An Intermediary Service Organization with Consumer Input

B. The IHSS Consumer Co-op: An Intermediary Service Organization with Maximal Consumer-Direction

C. Anticipated Outcomes Of The Project
   1. Four Co-ops: Two in the South; Two in the North
   2. Two Types of Developers: Regional Center Vendors and Independent Living Centers
   3. Planned Variation in Demonstration Sites

III. **OUTCOME: After three Years—No IHSS Consumer Co-ops in California**

A. Consumers were reluctant to start or join an IHSS consumer co-op
   1. Consumers were afraid to lose what little they had if they joined something new
   2. Consumers did not want to share their workers
   3. Inability of project sites to sustain Consumer Leadership

B. Disability Community Pre-Occupied with the Adoption of the Public Authority
   1. Counties Adopt the Public Authority

C. Counties were hesitant and unable to identify methods to implement the co-op, including funding the Co-op to administer IHSS for its members
   1. *Could* Counties Fund IHSS Consumer Co-ops?
      a. The Non-Profit Consortium
      b. The Contract Mode
III. OUTCOME (continued)

2. Would Counties Fund Co-ops?
   a. The Unique Case of San Diego
   b. Barriers to Counties Funding the Co-op
      1. Lack of Pre-Existing Models for the Co-op
      2. Lack of Pre-Existing Models for Redirecting Administrative Overhead to an Entity like the Co-op
      3. The Implementation of AB 1682--Counties Must Establish an Employer of Record for IHSS by 2003--more fuel for the Public Authority
      4. The Public Authority Sweeps California
   c. County Incentives to Fund the Co-op
      1. History of Serious Problems with the IP Mode
      2. The Importance of County Characteristics when Establishing an IHSS Consumer Co-op

IV. WHY DID IHSS CONSUMER CO-OPS FAIL TO FLOURISH IN CALIFORNIA?

A. Co-op Issues: Does the Co-op have Sufficient Added Value over the Public Authority?
   1. The Public Authority: An Effective Solution to Intermediary Services

B. Consumer Issues
   1. A Lull in Consumer Activism Statewide?
   2. IHSS Recipients have Limited Personal, Tangible, and Social Resources
   3. The Public Authority: Consumer Voice without Consumer Work

C. Poor Marketing of the Co-op
   1. What should be the Qualifications of the Co-op Developer?
      A Disability Expert or a Co-op Expert?

V. BROADER LESSONS

A. What did we Learn about Co-ops and Consumer-Direction?
   1. The Promise of More Consumer-Control was NOT Stronger than the Fear of Losing What Consumers Already Had
   2. A Preference for Self-Advocacy over Self-Help?

B. Is Social Capital a Pre-Requisite to the Development of a Consumer Co-op?

C. Is Social Capital Compromised for Individuals with Disabilities Living in the Community?

D. Have Developments within California's IHSS program led to a Passive Reliance on the State?

E. Should Co-ops for People with Disabilities be Abandoned?
   1. Co-ops Co-existing with the Public Authority: A Mechanism for Broad-based Consumer Involvement in IHSS?
   2. Co-ops can be a Structure for Building Social Capital for Individuals with Disabilities
WHY A COOPERATIVE?

A cooperative (co-op) is "an organization that is owned and controlled by the people who use its products, supplies, and/or services (U.S. Department of Agriculture, 1996)." Cooperatives vary in their particular purposes but share in common the fact that they are formed to meet the specific objectives of members, and structured to adapt to member's changing needs. Co-ops are fundamentally self-help organizations. They are democratically controlled on the basis of one vote per member. The co-op members elect a board which sets policies and is responsible for policy governance. The board usually hires a manager and additional staff to run day-to-day operations; however, some co-ops are staffed by its members.

CO-OP STORY: THE HMONG AMERICAN COOPERATIVE
The California Center for Cooperatives is partnering with the Hmong American Community, Inc. (HAC) to launch the Hmong American Cooperative that markets fresh vegetables grown by Hmong farmers in Fresno County. Approximately 60,000 Hmong reside in California’s Fresno and Merced counties, and about 600 Hmong families farm in Fresno County growing labor-intensive specialty crops on small 5-20 acre farms. This cooperative aims to provide these farmers with an opportunity to reach economic self-sufficiency through agriculture. "A cooperative will have a very great impact because it will give Hmong farmers marketing power," Hmong leader Toulu Thao says. "The people will learn about the business, about supply and demand, so they can better prepare themselves for competition. In the past, they have had no say, no understanding of what happens after they deliver their produce to the broker."
The history of cooperatives dates back to the Industrial Revolution. Cooperatives were useful for promoting the interests of the less powerful members of society. Workers, consumers, farmers, artisans, and others found that they could accomplish more collectively than they could individually.

Today, the cooperative business structure endures and continues to effectively serve its diverse member groups. In fact, one in three Americans is a cooperative member. The largest sector of cooperatives includes Credit Unions that serve their consumer members by providing financial services. Sunkist, Land of Lakes, and Blue Diamond are among a long list of farmer-owned marketing cooperatives that enhance member economic power. Cooperative housing models are flexible enough to include member-owners of condos on the most exclusive streets of New York, as well as member-owners of affordable housing for low-income families in Los Angeles. Cooperatives are so entrenched in the American system that there are federal tax and anti-trust laws that apply specifically to them, and incorporation codes in most states have specific statutes that apply to cooperatives.

“Cooperatives as a tool for building community strength.”

Produce Co-op

Child Care Co-op

Bike Co-op
1. Co-op structure allows its members (the people who use its services) to be active leaders in both identifying what they need and how those needs will be addressed.

2. Co-ops are a well established model with a long history of success.

3. Belonging to a co-op is inherently empowering because of the economic power created by members working together, the democratic decision-making, and the fundamental issue of ownership.
WHAT IS THE RELATIONSHIP BETWEEN COOPERATIVES AND THE RWJF INDEPENDENT CHOICES PROGRAM?

Individual empowerment and self-determination are essential components of consumer-direction. In writing about people with disabilities, Wehmeyer (1994) states that self-determination refers to the "attitudes and abilities necessary to act as the primary causal agent in one's life and to make choices and decisions regarding one's quality of life (p. 9)." It is well documented that people with disabilities may need supports to make decisions and choices about their lives; moreover, once these decisions and choices are made, they may also need supports to implement them. This is especially true for people who rely on personal assistance services.

Cooperatives are widely used to address the needs of the disabled.

In 1985 The Committee for the Promotion and Advancement of Cooperatives (COPAC) collaborated with the United Nations to publish a comprehensive guide to cooperatives of disabled persons. The report was published in five different languages. Today, cooperatives in various regions of Canada serve their cooperative members by providing consumer-directed home health care services. In the Philippines, the National Federation of Cooperatives of Persons with Disabilities serves members in Independent Living Centers. In Sweden, The Stockholm Cooperative for Independent Living provides a consumer-directed approach to meeting the needs of members. Countries with such consumer-directed cooperatives share in common health systems with at least some components of socialized medicine. This may be why consumer-directed cooperatives are not found in the United States.

Not that the issue of cooperatives that support the needs of Americans with disabilities has been overlooked. Cooperative Home Care Associates is a worker cooperative of home health aides that serves New York, Philadelphia and Boston. In 1995, Deborah Altus published Consumer Co-ops: A Resource Guide for Consumers with Disabilities as the final report of The Co-op Access Project (Institute for Life Span Studies at the University of Kansas) using funds from the National Institute on Disability and Rehabilitation Research. The report discusses a wide variety of potential cooperatives that could serve people with disabilities. The findings in this publication are similar to those revealed in this report—that the empowerment engendered by the cooperative model can provide the most consumer-directed approach for people with disabilities.

4For an extensive discussion of ISO's, see Flanagan & Green, 1997.
WHY A CO-OP FOR IHSS RECIPIENTS?

CALIFORNIA'S IHSS PROGRAM

In California, people who need personal assistance services are served through a program called In-Home Supportive Services (IHSS). The IHSS program in California is a "capped entitlement." State law clearly provides criteria for determining who is entitled to services but eligible persons can receive up to 283 hours unless protective supervision is authorized. California's IHSS program is the largest, publicly funded state home care program in the United States, serving over 190,000 individuals. Originally established in 1959 and subsequently amended in 1973 with the implementation of the Supplemental Security Income (SSI) program, the IHSS program authorizes per hour payments to providers who assist eligible aged, blind and disabled persons with limited financial resources to safely remain in their own homes. Services provided include assistance with Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs)\(^1\). Administration of this program is the responsibility of the California Department of Social Services (CDSS); however, each of California's 58 counties has unique authority over how this program is administered at the local level.

Although the state has made efforts to standardize the program, differences exist from county to county. Variables affecting service delivery include the number of IHSS consumers within the county (from 9 authorized cases in Alpine County to 91,315 in Los Angeles County\(^2\)) and the mode or modes of service delivery being utilized within the county.

Two mechanisms for receiving IHSS: IHSS residual program v. personal care services (PCSP) program

In California, there are two primary mechanisms for funding in-home supportive services: IHSS Residual Program, and Personal Care Services program (PCSP). Both of these programs provide assistance to eligible aged, blind, and disabled individuals who are unable to remain safely in their own homes without assistance. Both are statewide programs administered and implemented at the local (county) level. And, both have limits on the number of hours a consumer can receive (283 hours per month). The primary differences in the programs are what services are available, the type of service provider, and how the programs are funded.

IHSS Residual Program

The IHSS Residual Program is seen as a default program, providing assistance to only those consumers whose services are not eligible for federal (PCSP) funding. Common reason for ineligibility include (1) the use of family members as personal assistants, i.e., when services are provided by a spouse or a parent of a minor child, (2) when the consumer is using domestic or related services only, (3) when the service being provided involves protective supervision, or (4) when the consumer has chosen the advance pay method of paying their provider. State share for this program is 65% from the general fund, with counties providing the remaining 35% out of county funds.

\(^1\)http://www.dss.ca.gov/getinfo/faq/faqprogram.html
\(^2\)From IHSS Management Statistics Summary (Cal. Dept. of Social Services) for February, 1999
A Post-Mortem Analysis of the California PAS Consumer Co-op Project

Most IHSS recipients served through the PCSP program

The vast majority of IHSS recipients are served through the PCSP (Personal Care Service Program), which became effective in April, 1993. It is a program which provides personal care services to eligible Medi-Cal beneficiaries with funding shared through a mix of federal, state and local dollars\(^7\). Notably, this program reduces the county's portion of IHSS costs to 17.5% for those who are eligible (Barnes, Sutherland, & Johnson, 1995). Thus, there is a significant incentive for counties and the state to use the PCSP Program whenever possible.

Modes of IHSS service delivery

In California there are three legally authorized methods (modes) of IHSS service delivery through which IHSS consumers get the personal assistance services they need and are authorized to have. Of the three modes legally available to consumers, 92% of the IHSS recipients in California use one mode—the Independent Provider mode, reflecting California's long-term commitment to consumer-direction in its IHSS Program.

\(^7\)Title XIX of the Social Security Act (Medicaid) (50%), California general funds (32.5%), and county funds (17.5%).

County Homemaker/Chore Mode: In some counties, the IHSS program provides homemaker/chore services to IHSS consumers. These services are primarily limited to housecleaning, cooking, shopping, etc., so consumers tend to be less severely impaired. This mode is utilized by fewer than 1,000 IHSS clients statewide. Typically, it is used to serve multiple clients with low hours and clients whose behavior or personality traits make providing services difficult (Benjamin, 1996). Workers in this mode are county employees who are hired, supervised, and fired by the county.

Contract Mode: This mode is an alternative available in some counties for those consumers determined to be either unable and/or unwilling to self-direct or locate an IP. Due to the relatively high cost of this mode (two to three times the cost of the IP mode), it has been used primarily for consumers requiring a low number of service hours. In this mode, a home care agency or other entity is paid by the county to provide workers to consumers and schedules times that the worker will be available to consumers. In this mode, the worker is an employee of the home care agency.

The contract mode is viewed as the least consumer directed in IHSS, as the consumer has little voice in selecting, hiring, supervising, or firing the individual.
Independent Provider (IP) Mode

The vast majority (92%) of California's IHSS population utilizes the IP mode of service delivery. In this mode, individuals authorized to receive IHSS must recruit, hire, train, supervise, and fire their workers. The California Department of Social Services (CDSS) considers Independent Provider (IPs) to be employees of the consumer; therefore there is minimal involvement by county IHSS personnel. IPs typically earn minimum wage. Consumers sign the timecards of workers; the county then processes the timecards and the state pays workers directly. Because the IHSS provider is considered an independent contractor, "employed" by the consumer, the county carries no liability. The State serves as a fiscal agent, handling social security, state disability, unemployment insurance, and worker's compensation.

In theory, the IP mode is the most consumer-directed of all of the modes available because the IHSS recipient has authority to recruit, hire, train, supervise, and fire their workers. It is also the preferred mode of consumers, suggesting the importance of consumer control over their personal assistance services for most IHSS recipients in California.

While the IP mode is clearly the preferred mode for consumers in California, the program has historically been built on an "all or nothing" foundation, i.e., "If you want to be in charge of your worker, then you're on your own." It is well documented that while consumers want a say in how they receive their personal care services, they also frequently need supports in their employer functions. Some do not know how or where to advertise for workers; some cannot afford to advertise for workers; some don't know how to orient and train their workers; some are confused by the timecard that needs to be filled out, to name a few. IHSS hours cannot be used to pay someone to assist the consumer with these employer functions.

In addition, many have no back-up if their worker does not show up. Consequently, they either have their health or safety compromised by trying to get through their daily routine alone, or they are forced to utilize "911" to get out of bed—an expensive alternative to IHSS. Many do not feel assertive enough to correct their workers or fire them when appropriate. Many accept a sub-standard level of care because they fear they will never get a replacement if their current worker leaves. They fear retribution if they report a crime or incidents of abuse/neglect. These compromises are fueled by threat of nursing home care if IHSS fails.

Mixed Modes: Counties have the option of offering more than one mode to recipients. All counties must offer the IP mode if a recipient prefers it.

Enhancements to the IP Mode--Intermediary Service Organizations

In recognition of the need of some consumers for supports in utilizing the IP mode, California implemented two enhancements to the IP mode: The Supported Independent Provider model and the Public Authority. Essentially, these enhancements to the IP mode are intermediary service organizations. A description of each of these follows.

* True at the time of this project.
The Public Authority is an incorporated public body, separate from the county, that exercises governmental functions and provides for the delivery of IHSS. As an enhancement to the IP mode, the Public Authority assists individuals in the IP mode to find, recruit, hire, train, supervise, and fire their workers. Moreover, the Public Authority is required to provide a registry of workers, investigate the background of applicants for the registry, provide a referral system and provide for worker and consumer training. As such, the Public Authority functions as an "Intermediary Service Organization". The Public Authority is considered the employer of record for IHSS workers related to collective bargaining and liability due to negligence or intentional torts of IHSS personnel.

AB 1682 contains provisions which offer an historic opportunity for consumers to be meaningfully involved in the process of determining the mechanism that counties choose for the Employer of Record for IHSS. Sections of the law explicit define that a Consumer Advisory Committee must be selected prior to any action by a Board of Supervisors. As such, they have the opportunity to select a mode of administering IHSS that best meets their needs and preferences. Although counties are experiencing difficulty finding qualified consumers to sit on their Consumer Advisory Committees and there are no explicit requirements for training and supporting consumers who serve in this capacity, the potential for influencing how IHSS services are delivered is higher than ever before.
Table 1 shows a comparison of the features of the various modes of IHSS service delivery and enhancements in California. As can be seen, the co-op and the Public Authority have many similar features of potential interest to counties. They each shield the county from liability, become the employer of record for collective bargaining purposes, and have the capacity to provide intermediary services to assist consumers in the IP mode, while allowing the consumer to stay in charge of their worker.

### Table 1. Comparison of Different Modes of IHSS Service Delivery and Enhancements in California

<table>
<thead>
<tr>
<th>Modes and IHSS Service Enhancements</th>
<th>Employer of Record</th>
<th>Severity of Need Typically Met by this Mode</th>
<th>Level of Consumer-direction</th>
<th>Worker Status</th>
<th>Cost per hour</th>
<th>Worker Benefits</th>
<th>County Liability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independent Provider (IP)</td>
<td>Consumer</td>
<td>All</td>
<td>High*</td>
<td>Independent Contractor</td>
<td>min. wage⁹</td>
<td>None</td>
<td>No</td>
</tr>
<tr>
<td>Contract</td>
<td>Contract Agency</td>
<td>Moderate¹⁰</td>
<td>Low</td>
<td>Agency Employee</td>
<td>10.95/hr¹¹</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Homemaker/Chore</td>
<td>County</td>
<td>Mild</td>
<td>Low-Mod.</td>
<td>County Employee</td>
<td>&gt; min. wage</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Supported Independent Provider (SIP)</td>
<td>Consumer</td>
<td>Mild-moderate</td>
<td>Low-Mod.</td>
<td>Independent Contractor</td>
<td>min. wage</td>
<td>None</td>
<td>No</td>
</tr>
<tr>
<td>Public Authority</td>
<td>Public Authority</td>
<td>All</td>
<td>Mod.-High**</td>
<td>Independent Contractor</td>
<td>&gt; min. wage</td>
<td>Some</td>
<td>No</td>
</tr>
<tr>
<td>Co-op¹²</td>
<td>Co-op</td>
<td>All</td>
<td>Highest</td>
<td>Co-op Employee</td>
<td>&gt; min. wage</td>
<td>Some</td>
<td>No</td>
</tr>
</tbody>
</table>

* "High" in theory - In reality, consumer direction may be compromised due to lack of supports
** depending on how the PA is implemented

---

⁹ $4.82/hr as referenced in an RFP of the San Mateo County Public Authority (1997)
¹⁰ Some studies show that contract agencies tend to provide fewer hours to less severely impaired IHSS recipients (see Barnes, 1995).
¹¹ Referenced in an RFP of the San Mateo County Public Authority (1997); actual costs may vary from county to county.
¹² Co-op description is in theory only.
THE IHSS CONSUMER CO-OP: AN INTERMEDIARY SERVICE ORGANIZATION WITH MAXIMAL CONSUMER-DIRECTION

A consumer's ability to influence the quality of service received is limited due to small unorganized "one consumer/one provider" enterprises which typify the IP mode.

The IP mode is built on a one consumer/one provider model of service delivery. In theory, it provides for consumer control of IHSS by recipients, but by its nature the IP mode encourages isolated, individualized efforts which may not be the most efficient and effective for meeting consumer needs.

The California PAS Consumer Co-op Project was designed on the assumption that consumer co-ops for IHSS recipients could be an effective method for providing the intermediary supports necessary for people with disabilities to recruit, hire, train, and supervise their personal assistants and create a forum for maximum consumer-direction in how these services are provided.

Figures 1 & 2 show how an IHSS recipient in the IP mode benefits by cooperating with other IHSS recipients—replacing the "one consumer/one provider" business relationship with an IHSS Consumer Co-op. It is this concept which underlies the innovation proposed in this Project.

Through the leveraged resources available by "pooling" and "sharing" workers of individual IHSS recipient-members and implementing collective solutions to individual problems (e.g., advertising for workers), the co-op (like the Public Authority) could address many of the problems experienced by consumers in the IP mode. First, the co-op would have the capacity to run its own registry, recruit and train providers working for co-op members, assist and support members having difficulty with workers, provide emergency back-up services to members, assist with fiscal responsibilities, and create efficiencies which would allow its members to get better services. Second, the co-op could establish standards for the type and quality of IHSS service delivery that are preferred by its members. In essence, individual members would have more say in defining how their IHSS is provided as the co-op hires, supervises, and fires co-op staff. Third, because the co-op would be the employer of record for workers, the co-op in theory could potentially implement strategies to raise salaries and provide benefits (e.g., health insurance) to workers, that the "one consumer/one provider" model cannot. This would begin to address the common problem of high turnover in the Independent Provider workforce. Finally, the co-op could represent the interest of its members as a collective, thereby speaking with a louder voice when issues arise with county/state policies and other stakeholders (e.g., labor unions). As with most co-ops, co-op functions would be provided by paid co-op staff. In some instances, some functions may be provided by co-op members. How to staff the co-op would be the decision of its members.
The democratic election of the Board of Directors for the Co-op gives individual members straightforward administrative control over what services are provided to members, and how those services will be provided. As can be seen in Figure 3, this member-controlled governance structure creates an enhancement to the IP Mode which is, in theory, more consumer-directed than the Public Authority.

Figure 3. Variation in Consumer Voice by IHSS Service Delivery Models

<table>
<thead>
<tr>
<th>Contract Mode</th>
<th>Public Authority</th>
<th>IHSS Consumer Co-op</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Consumer Direction</td>
<td>Maximal Consumer Direction</td>
<td></td>
</tr>
</tbody>
</table>

See Table 2 for a summary of the difference in "consumer-direction" between the Public Authority and the IHSS Consumer Co-op.

Table 2. Comparison of the Public Authority and the Consumer Co-op Consumer Voice

<table>
<thead>
<tr>
<th>Type of Intermediary Service Organization</th>
<th>Type of Organizational Structure</th>
<th>Type of Consumer Input</th>
<th># of Consumers</th>
<th>How Consumers are Selected</th>
<th>Authority of Consumer Body</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public Authority</td>
<td>An incorporated public body with governmental function</td>
<td>Advisory</td>
<td>51%</td>
<td>Appointed by Board of Supervisors</td>
<td>•Advise Public Authority Staff</td>
</tr>
<tr>
<td>IHSS Consumer Co-op</td>
<td>An incorporated member organization</td>
<td>Board of Directors</td>
<td>100% *</td>
<td>Elected by co-op members (consumers)</td>
<td>•Hire, supervise, fire co-op staff •Fiscal/program monitoring</td>
</tr>
</tbody>
</table>

* Because the Board of Directors is elected by co-op members, and the co-op membership consists of IHSS Recipients, the Board could be 100% consumers. The membership could vote to include a percentage of Board Members who are from another class of individuals, e.g., workers, professional advisors. Also, if the co-op were a consumer/worker co-op, IHSS workers would be members and potential candidates for Board membership, depending on the composition of the Board as defined by the Co-op's by-laws.
ANTICIPATED OUTCOMES OF THE PROJECT

Four Co-ops: Two in the South Two in the North
The California PAS Consumer Co-op project proposed to develop and evaluate IHSS Consumer Co-ops in four counties in California: two in northern California and two in southern California. Two were to be developed by Independent Living Centers (ILC's): Community Resources for Independence in Sonoma County and The Dayle McIntosh Center in Orange County, and two by regional center vendors: Creative Support Alternatives in San Diego, and Training Towards Self-Reliance in Sacramento.

Two populations were specifically targeted: individuals with adult onset physical disabilities, who are frequently served by independent living centers, and individuals with developmental disabilities who are served by regional centers.

Two Types of Developers: Regional Center Vendors
Individuals with developmental disabilities in the state of California receive entitlement services through a system of 21 regional centers established under state legislation, the Lanterman Developmental Disabilities Services Act (Lanterman Act). Clients eligible for regional center services must have a disability which occurred before the age of 18 years of age, is likely to require substantial supports for an extended period of time and is due to one of the following diagnostic conditions: Mental Retardation, Autism, Cerebral Palsy, Seizure Disorder, or any condition resembling the services and supports needed by a person with mental retardation. Under the Lanterman Act, regional centers assist eligible clients with service coordination, including applying for and accessing generic services (e.g., Medicaid, SSI, and IHSS). They can also purchase services (Purchase of Services "POS" dollars) that a client needs, but which are not provided otherwise. In theory, regional centers could use POS dollars to enhance a client's utilization of the IHSS program (e.g., assistance in finding IHSS workers, training and supervising workers, completing timecards, etc.).

Two Types of Developers: Independent Living Centers
IHSS recipients who are not eligible for regional center services include individuals whose disabilities are due to advanced age and/or young adults whose disabilities occurred after the age of 18, or include diagnostic conditions not covered under the Lanterman Act. These clients are frequently served by independent living centers (or area agencies on aging for the elderly). As such, they may have access to training on how to be an effective employer, and depending on the independent living center, may also have access to a registry of personal care assistants (not an IHSS registry per se). Moreover, ILC's are well known for their advocacy work around all issues facing the independence, autonomy, and full community participation of individuals with disabilities. IHSS is a prominent generic service that ILC's are actively involved in.

The variation in demonstration site developers was planned to examine possible differences in the co-op model developed, which might be influenced by differences in the targeted IHSS population, the service systems available to them for supports, and geography.

Planned Variation in Demonstration Sites
The project started with four pilot sites designated by county: Napa/Sonoma County (Community Resources for Independence (CRI)), Sacramento County (Training Towards Self-Reliance (TTSR)), Orange County (Dayle McIntosh Center for Independent Living (DMC)), and San Diego County (Creative Supports Alternatives, San Diego State University(SDSU)). Each demonstration site agency (DSA) was provided with a small grant each year to support co-op development activity in their counties over a 3-year period. The specifics of their activities were locally determined; however, several common strategies were implemented across all sites because they were viewed as having broad applicability, such as (a) identifying and cultivating consumer leadership for the co-op development team, (b) developing or further strengthening a close relationship with county IHSS personnel, and (c) developing a business plan for the co-op.
After three years of intensive work in two counties\textsuperscript{13}, exploratory work in five additional counties\textsuperscript{14}, and consideration of the co-op by four other counties\textsuperscript{15}, we were not successful in establishing an IHSS Co-op for consumers. San Diego County had the greatest success by negotiating a 3-year multi-million dollar contract for a demonstration project which would establish the Consumer Co-op for the severely impaired in San Diego. However, by the end of a 4\textsuperscript{th} no-cost extension year, San Diego was still waiting for federal and/or state waivers to implement the demonstration project, and had adopted the Public Authority.

The following is an analysis of possible reasons for this lack of success.
FINDING: IHSS Recipients in California did not want to start or join an IHSS Consumer Co-op

On the whole, throughout the project, we were unable to solicit a critical mass of consumer interest in the co-op and/or mobilize consumers to advocate for its implementation within the county (with the exception of the San Diego site, which is discussed throughout this report).

Original Pilot Sites. In spite of varying methods for community outreach, two of the original pilot counties, Napa/Sonoma and Orange Counties experienced significant difficulty soliciting consumer interest in the co-op. Community Resources for Independence (CRI), a well-established independent living center in Napa/Sonoma County, held numerous meetings with key disability leaders, but found these leaders could not see how an IHSS consumer co-op in their county could provide better solutions to the recognized deficiencies within the existing system, that an expansion of the visiting nurse program already in existence there could provide. CRI withdrew from the project after one year.

The Dayle McIntosh Center (DMC), also a well established/well respected independent living center in Orange County, conducted community outreach activities for three years utilizing a variety of techniques, including inviting IHSS recipients to informational sessions in the community and marketing through radio announcements in the first year, conducting targeted informational sessions in senior and disability housing complexes and attempting one-on-one personal outreach in these housing developments in the second and third years. Throughout the three years of community outreach, DMC was unable to recruit more than 2-3 consumers to co-op development meetings, with "no-shows" at the majority of meetings.

Geography does not appear to be a factor as Napa/Sonoma is a northern California county, whereas Orange County is in the south. Both co-op development agencies were well-established independent living centers with excellent relationships with county leaders of their IHSS program. Both agencies have majority consumers in leadership and staff positions, so fully understand and practice consumer-driven service delivery. The Executive Directors of both agencies were key developers of the proposal submitted for this project and therefore, were predisposed to the concept of an IHSS Consumer Co-op.

Without consumers strongly advocating for the co-op, county IHSS programs were, in turn, not willing to invest in the innovation. Had counties been willing to initiate the co-op, consumers may have been more willing to consider joining it. The Project was caught between a rock and a hard place. What were some reasons consumers were not interested in starting or joining an IHSS Consumer Co-op?
Consumers worried that they would lose what little they already had

Regardless of the pilot site, consumers who attended project organizational and informational meetings uniformly filed many complaints about what was wrong with the IHSS program, including finding and keeping good workers, having no back-up when a worker didn't show up, problems with training new workers, costs associated with recruiting and training workers, not enough hours of service, no help arranging services, etc. However, in spite of many perceived problems with the IHSS system, most consumers did not want to join something that was not well established, something that might not survive. They were most worried about possibly losing their existing services, no matter how imperfect.

Consumers not willing to share their workers--feared they would lose their workers to others

A surprising finding of the project was the general unwillingness of consumers to share their current workers with other co-op members. One of the benefits which the co-op could offer its members was to provide for emergency back-up services. One method for achieving this was the operation of a worker registry by the co-op, using the efficiencies of workers currently employed by co-op members as part of the registry pool. While consumers wanted and needed emergency back-up services, they were frequently reluctant to share their own workers with others, out of fear that they would lose their worker.

---

16 Our assurances to consumers that if they did not want to continue their membership with the IHSS co-op, they, by law, could go back to their original mode of service, did not override their concerns about losing what little they had.
"What if my worker likes another consumer better than me?" was a frequently asked question when discussing the possibility of sharing workers.

The possibility of having greater control over their IHSS services was not as important as the perceived threat to consumers that they might lose what little they already had.

**Inability of project sites to sustain Consumer Leadership**

Another key finding of this project was the inability of project sites to sustain consumer leadership and involvement in the co-op development process. Orange County's work was a good example of this. This project's co-op development team initially identified two IHSS recipients who were interested in identifying alternatives to current IHSS service delivery in Orange County. Their attendance at meetings, however, was frequently at some cost to the individual, as they had to "pay" their workers to assist them to get to and participate in meetings. Moreover, health problems were a constant threat to regular attendance.

When new leadership was identified, the lack of leadership experience and skills led to friction between the new and old leadership, eventually resulting in the new leadership losing interest in the project.

While this group was majority consumers who were past or current users of personal assistance services, only a few were current IHSS recipients (others were private pay). Moreover, they also had membership and commitment from key stakeholders including the veterans group, Area Agency on Aging, independent living center, and direct support workers. Members of this group were politically connected, had expertise in business development, and had personal resources to develop the co-op business plan. The co-op developer in this county was a university-based professional with excellent writing and communication skills.

These factors suggest the possible advantages of consumer/professional leadership in IHSS co-op development and the need for business expertise and political savvy in the co-op development team.

**The Unique Case of San Diego**

The importance of sustained consumer leadership was exemplified in the one county which was successful in obtaining commitment from county IHSS to establish an IHSS consumer co-op for the severely impaired. Notably, the co-op development team in San Diego County consisted of a pre-existing IHSS Leadership group which had been active for three years prior to this project and continued to be active throughout the three years of this project as well.
FINDING: Disability Community Pre-occupied with the Adoption of the Public Authority

For nearly a decade, workers and consumers have collaborated to establish Public Authorities in California to administer the IHSS program, in an effort to provide relief and support to consumers in the IP mode and improve working conditions for workers (independent providers). The chief drawback of the independent provider IHSS Program has historically been the lack of a referral/registry system to do background checks, link consumers and workers, and provide emergency and substitute workers. By performing these functions, as well as coordinating access to training and case management for those who need it, the Public Authority has been promoted by Service Employees International Union\textsuperscript{17} and consumer groups over the years as a means to improve the quality of IHSS services, without interference to consumer control.

\textsuperscript{17} SEIU is one of two labor unions representing home care workers in California. The other labor union is United Domestic Workers. Each county in California has been assigned to one of these two unions.
The following is a chronology of the historical foundation underlying the Public Authority, which speaks to the complexity of adopting innovation within California’s IHSS program, and the length of time it has taken to institutionalize the Public Authority.

In 1991, California’s Health and Welfare Agency convened a task force on Long Term Care/IHSS (LTC/IHSS) as was required in the legislation that enacted State/Local Program Realignment. The LTC/IHSS Task Force was charged with a variety of tasks, including working on issues to allow counties to form IHSS authorities and to develop registries of persons willing to work in the IHSS program. In 1993, the Legislature passed two urgency measures (SB 35 and SB 1078) to authorize counties to establish Public Authorities to administer the IHSS program. Subsequent legislation passed in 1994 (AB 1354) made technical corrections to the 1993 statutes. This legislation anticipated the need for both a State Plan Amendment regarding Medi-Cal’s reimbursement methodology for personal care services (which would require federal approval) and new state regulations in order to implement Public Authorities.

In April of 1994, the State Department of Health Services submitted the required State Plan Amendment (SPA) 94-006 to the Health Care Financing Administration for review and approval. The California Legislature passes SB 1780 as a budget trailer bill to clarify that the Public Authority is not a fourth mode of service and that the Public Authority has the authority to administer both the individual provider mode and the contract mode. SB 1780 also restricts state funds and requires that counties must bear the non-federal cost of wages and benefits for individual providers above the state minimum wage.

Followed with clarifying information in November 1994. The federal government approved the State Plan Amendment on January 25, 1995 -- enabling California to proceed with the development of the necessary regulations. These regulations are authorized under Welfare and Institutions Code § 12301.6 (k) (1) (2) (3), which also allows the Department to issue the regulations as emergency regulations without the normal review of the Office of Administrative Law and further specifies that the regulations shall take effect immediately upon filing with the Secretary of State.

### Events Leading to the Public Authority

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>1991</td>
<td>Ca. Health and Welfare Agency convenes task force on Long-Term Care / IHSS to address problems with the IHSS program</td>
</tr>
<tr>
<td>1993</td>
<td>SB 35 &amp; SB 1078 authorizes counties to establish Public Authorities to administer the IHSS program.</td>
</tr>
<tr>
<td>April, 1994</td>
<td>Ca. Department of Health Services submits the required State Plan Amendment, necessary to implement the P.A., to HCFA for review and approval.</td>
</tr>
<tr>
<td>April, 1995</td>
<td>Ca. Department of Social Services puts into circulation draft regulations regarding the Public Authorities for the provision of In-Home Supportive Services [WIC 12301.6]</td>
</tr>
<tr>
<td>May-July, 1995</td>
<td>Stakeholders workgroup convenes to provide input on draft regulations</td>
</tr>
<tr>
<td>1996</td>
<td>California Legislature passes SB 1780 as a budget trailer bill to clarify that the Public Authority is not a fourth mode of service and that the Public Authority has the authority to administer both the individual provider mode and the contract mode. SB 1780 also restricts state funds and requires that counties must bear the non-federal cost of wages and benefits for individual providers above the state minimum wage.</td>
</tr>
<tr>
<td>1997</td>
<td>AB 67 passes, requiring state participation in non-federal administrative costs of P.A.</td>
</tr>
</tbody>
</table>
On April 19, 1995, the State Department of Social Services put into circulation draft regulations regarding the Public Authorities for the provision of In-Home Supportive Services. A workgroup was established to provide input from key stakeholders and three meetings were held between May and July, 1995, on the regulations.

In 1996, the California Legislature passed SB 1780 as a budget trailer bill to clarify that the Public Authority is not a fourth mode of service and that the Public Authority has the authority to administer both the Independent Provider mode and the Contract mode. SB 1780 also restricted state funds and required that counties must bear the non-federal cost of wages and benefits for individual providers above the state minimum wage. This measure also clarified that no wage or benefit increase for independent providers may take effect until the State Department of Social Services receives the approval of the State Department of Health Services and that it is consistent with federal law and to ensure federal financial participation for the services under Title XIX of the federal Social Security Act. In 1997, AB 67 (Chapter 606, Statutes of 1997) was passed as a budget trailer bill to require state financial participation in the non-federal administrative costs of the Public Authority in accordance with existing sharing ratios.

Coming at the heels of essentially six years of organized work by consumers, advocates, and the labor union to get counties to consider and adopt the Public Authority, our efforts to establish IHSS Consumer Co-ops in California was seen as a nuisance, threat, or undesirable diversion to consumers and counties advocating for the Public Authority model. It was the reason for moving our original efforts in Sacramento to Yolo County; and the reason why initial interests by consumers in Los Angeles, Contra Costa, and Long Beach were aborted. All of these counties had already created a platform for the Public Authority, which they hoped their Boards of Supervisors would approve.

At the beginning of this project, three counties had Public Authorities; by the end of the project period (June, 2001), five additional counties had voted to establish Public Authorities (one of these being Los Angeles County with the largest union enrollment of workers in U.S. history). While the disability community and SEIU were not against the co-op in principle, the timing was very poor. There was too much at stake in getting the Public Authority adopted in other counties, which the co-op could threaten.
FINDING: Counties were hesitant and unable to identify methods to implement the co-op, including funding the Co-op to administer IHSS for its members

Could Counties Legally Contract with the IHSS Consumer Co-op to Administer IHSS for Co-op Members?

Co-ops do not function just because there is a need and people have come together. Collective solutions must then be implemented and the more complex the solutions, the greater the need for skilled, reliable staff. Staffing of co-ops can be provided by the voluntary effort of members or by paid staff. For the IHSS Co-op to have value for its members, it must provide the intermediary services described earlier in this report. The provision of these services will require the services of paid staff. In some co-ops, staff are paid through membership dues. However, membership dues are not an option for most IHSS recipients, many of whom live on fixed, minimal incomes. Because of these realities, we focused heavily on conceptualizing the co-op in a manner that would allow counties to “contract” with the co-op to administer the IHSS program for its members.

This required an analysis of potential legal and regulatory barriers to funding the IHSS Consumer Co-op, which was conducted by consultant Eldon Luce. We found that there are two legal mechanisms for counties to fund the co-op to administer IHSS for its members.

The Non-Profit Consortium
If the co-op incorporated (with other agencies) as a non-profit consortium (as described in OMB Circular A-122 found at Federal Register, Vol. 45, No 132, dated July 8, 1980), the county (if directed by the Board of Supervisors) could contract with the co-op through its corporate structure as a Non Profit Consortium, to administer IHSS services for a portion or all of the IHSS recipients in the county (Welfare and Institutions Code 12301.6a). The Non-Profit Consortium is an association that has a tax exempt status and meets the definition of a non-profit organization. It must have the following characteristics:

- A Governing body or an advisory committee of no more than 11 members; no fewer than 50% of its members shall be consumers (current or past user of PAS)
- Provide the following services: assistance in finding providers through establishment of a registry; investigation of qualifications and background of potential providers; establish a referral system to match providers with recipients (registry); access to training for providers and recipients; any other function related to the delivery of IHSS

Ironically, this provision is contained within the same statute that authorizes the Public Authority.
• Is deemed the employer of record for IHSS personnel for purposes of collective bargaining and liability
• Submit cost reports and other data as required for Case Management, Information, and Payrolling System (CMIPS)
• The IHSS Recipient retains the right to hire, fire, and supervise the work of any IHSS personnel providing services to them
• The state continues to take responsibility for payroll, unemployment insurance, and worker’s compensation
• Costs of the consortium will be funded from the County’s Services Allocation
• The Consortium will develop a budget which includes all administrative costs, and costs for IHSS services

As can be seen, the Non-Profit Consortium is almost identical to the Public Authority. However, no county has ever contracted with a Non-Profit Consortium, in spite of its legality as an entity to administer IHSS. This lack of precedent created an additional barrier for counties feeling comfortable with the co-op.

**Contract Mode**

Counties could also contract with a Co-op, if the co-op met the requirements for a contractor. We did not consider this a viable alternative because of the regulations governing contractors, which require such high levels of capital that small incorporated entities would have difficulty meeting these requirements. Moreover, few counties in the state utilize the contract mode, so for many counties, contract mode was not a familiar avenue for providing IHSS services.

---

**Would Counties Fund Co-ops?**

The Unique Case of San Diego: Negotiated a multi-million dollar contract with the County for a Co-op

A surprising finding of this Project was that the single potentially successful co-op in the state (San Diego) was to be funded under the contract mode. The co-op’s ability to meet the heavy requirements of contractors was addressed through establishing the co-op as a demonstration project, which would allow the county to waive some of these requirements. It was the process of obtaining demonstration project status and the related requests for waivers, which significantly delayed the implementation of the co-op in San Diego, in spite of full county commitment to fund the co-op and Governor’s set aside in the 2000-2001 budget for the co-op demonstration. By the end of the no-cost extension 4th year (September, 2001), the San Diego project had not received approval for the waivers requested.
<table>
<thead>
<tr>
<th>Date</th>
<th>Event Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>11/93</td>
<td>Group of IHSS Consumers and advocates meet with Director of Dept. of Social Services to request the formation of a task force to examine service delivery options for IHSS Consumers who are severely impaired. Task force approved.</td>
</tr>
<tr>
<td>3/94</td>
<td>IHSS Coalition has first meeting to examine pros and cons of establishing a Public Authority</td>
</tr>
<tr>
<td>12/95</td>
<td>Board of Supervisors directs CAO to access $50,000 to study Public Authority and IHSS</td>
</tr>
<tr>
<td>2/96</td>
<td>Warren Cantrall has feet burned in tub of hot water prepared by his IP. Files lawsuit against County because county social worker recommended the IP.</td>
</tr>
<tr>
<td>9/96</td>
<td>Study of IHSS begins</td>
</tr>
<tr>
<td>4/97</td>
<td>Final Report of study submitted, recommending SIP model in San Diego and establishment of an IHSS Leadership Group</td>
</tr>
<tr>
<td>5/97</td>
<td>Board of Supervisors approves IHSS Leadership Group and designates it as a formal sub-committee to the Social Services Advisory Board.</td>
</tr>
<tr>
<td>7/97</td>
<td>Co-op project begins.</td>
</tr>
<tr>
<td>9/97</td>
<td>IHSS Leadership Group agrees to become Co-op development Team</td>
</tr>
<tr>
<td>1/98</td>
<td>Two social workers hired by AAA begin Registry development for IHSS</td>
</tr>
<tr>
<td>2/98</td>
<td>Superior Court rules in favor of Cantrall.</td>
</tr>
<tr>
<td>6/98</td>
<td>IHSS Leadership Group submits their final report. Co-op is mentioned in the report. Board commits to real improvements at affordable costs. Two procurement processed led to no new contractors identified. Contracting process viewed as biased in favor of large for-profit companies. AAA recommends that contracting process for IHSS be modified. County commitment to work with co-op developer to further develop the co-op concept.</td>
</tr>
<tr>
<td>8/98</td>
<td>Proposal for IHSS Consumer co-op submitted to County IHSS staff and CFO.</td>
</tr>
<tr>
<td>10/98</td>
<td>Co-op proposal edited and resubmitted to County.</td>
</tr>
<tr>
<td>11/98</td>
<td>Co-op development team meets with San Diego Committee for Persons with Disabilities. Committee writes support letter to board of supervisors.</td>
</tr>
<tr>
<td>2/99</td>
<td>Co-op proposal edited and resubmitted to County with support letters from major stakeholders</td>
</tr>
<tr>
<td>1/99</td>
<td>Co-op proposal submitted to Board of Supervisors for vote. CFO gives the proposal full support. Board votes to accept proposal. Instructs county staff to submit proposal to the State Dept. of Social Services for demonstration project status to solicit state share of funding for the demonstration.</td>
</tr>
<tr>
<td>3/99</td>
<td>San Diego County submits request for demonstration project to California Department of Social Services (CDSS). Asked to rewrite proposal using specific format.</td>
</tr>
<tr>
<td>7/99</td>
<td>Proposal resubmitted to CDSS with revisions.</td>
</tr>
<tr>
<td>3/00</td>
<td>Karen Keesler (lobbyist) working pro bono with county lobbyists on behalf of co-op</td>
</tr>
<tr>
<td>4/00</td>
<td>CDSS Legal renders determination that a federal waiver is needed because proposal is limiting participants to individuals with severe impairments. CDSS reports that HCFA interested in the Co-op.</td>
</tr>
<tr>
<td>5/00</td>
<td>Delegate letter encouraging state's approval of the demonstration project proposal, signed by Assembly Representatives and State Senators from San Diego sent to CDSS. Recommended in Governor's budget.</td>
</tr>
<tr>
<td>6/00</td>
<td>Co-op included in Governor's budget.</td>
</tr>
</tbody>
</table>

---

San Diego Co-op Development History

**From IHSS Leadership Group Final Report, San Diego County, June 10, 1998**
Barriers to Counties Funding the Co-op

Our experience revealed many disincentives for counties to fund the co-op.

No Pre-Existing Models for a Co-op

Most county administrators were not inclined to break new ground. Hence, there were constant requests for evidence of IHSS co-ops which had been successfully executed and or piloted in other counties. Co-ops for people with disabilities who use personal assistance services have a long history in Europe (cf. Frehse, 1993; Konkkola - Sjovall, 1993; Ratzka, 1993) and in Canada (Wetherow, 1998). However these have not been replicated in the U.S. While generic co-ops were numerous in California, disability co-ops were (and are) essentially non-existent in the state. Even the staff of the Center for Cooperatives at UC Davis, a longstanding state-funded program to promote co-op development in California, was familiar with, but had no experience with disability co-ops. Similarly, while clearly articulated in statute, the legal mechanism identified by our project for counties to contract with the co-op (the Non-Profit Consortium) had no precedent in the state. Consequently, counties were generally reluctant to try the IHSS Consumer Co-op.

Supporting the importance of this variable, the one almost-successful county, San Diego, proposed to utilize the contract mode to fund the Co-op. San Diego, home of the United Domestic Workers union, was one of the few counties in California which had utilized the contract mode for over twenty years; hence, funding the co-op using this mechanism was not a major departure from existing practice.

Redirecting Administrative Overhead to the Non-Profit Consortium: A Potential Threat to existing County IHSS staff

The IP mode requires county staff to conduct assessments and to provide whatever assistance to IHSS recipients the county chooses to provide. Consequently, in most counties in the state, the establishment of a co-op would impact existing county positions, if administrative funds were redirected to the IHSS Consumer Co-op. This represented a significant disincentive to many counties. Again, San Diego's history as a contract/IP mixed mode county made it more amenable to funding the co-op through the contract mode.

Implementation of AB 1682: Counties Must Identify an Employer of Record for IHSS by 2003—More Fuel for the Public Authority

In the third year of the project, Assembly Bill 1682 was passed which required every county in California to establish an employer of record by the year 2003. Representing a concerted effort by labor unions for independent providers and home care workers, this bill created major incentives for counties to identify an entity separate from the county to administer IHSS for eligible citizens. The IHSS Co-op suddenly had potential value to the county. In the two counties where co-op development was still active (Orange County and San Diego County), the county’s interest in the co-op heightened (although San Diego was already interested in the co-op for other reasons). In Orange County, the coincidental change in IHSS leadership (due to retirement of the previous director) and the anticipated implementation of AB 1682, resulted in strong encouragement by county IHSS for the inter-agency co-op development team to incorporate as a non-profit consortium. However, in spite of efforts to
identify collaborators for a Non-Profit Consortium, progress towards this end was not forthcoming. Orange County IHSS chose to consider adoption of the Public Authority instead.

**The Public Authority Sweeps California**
Because the Public Authority represented a "known" entity, with three counties successfully implementing it for 3-5 years, and four other counties in the process of voting for the Public Authority, its attractiveness to counties was implicit. The co-op could not compete with the long history and the coordinated marketing effort behind the Public Authority. The co-op made its debut at the heels of the Public Authority--several years after consumers, advocates, and labor leaders joined forces to create this innovative consumer-responsive solution to the intermediary service needs of IHSS recipients in the IP mode.

**County Incentives to Fund the Co-op**

**History of Serious Problems with the IP Mode Requiring County Remedies**

*Cantrall v. County of San Diego.* In February, 1996, Warren Cantrall, an IHSS consumer in San Diego County, had his feet accidentally burned in a tub of hot water, which had been prepared for him by his Independent Provider. The IP had been referred to Mr. Cantrall by a county IHSS social worker. Mr. Cantrall filed a personal injury lawsuit against San Diego County. In February, 1998, the Superior Court returned a verdict in favor of Mr. Cantrall requiring that the County pay all costs of plaintiff's medical bills and compensation for pain and suffering. The co-op concept was developed jointly by the IHSS Leadership Group and County IHSS during the Cantrall decision (beginning in September, 1997), leading to a vote by the Board of Supervisors to accept the proposal in January, 1999--approximately 15 months after the beginning of the Project. Clearly many other factors were operative in this success (including the talent of the co-op developer in San Diego, the wisdom in convincing the already existing IHSS Leadership Group to advocate for the co-op as a solution to San Diego's IHSS problems; the advocacy of the Chief Financial Officer for San Diego who presented the co-op and a budget to support it to the Board of Supervisors). However, the openness of the County IHSS program to the Co-op concept was likely influenced by the county context created by the Cantrall lawsuit. The timing was good in San Diego for the co-op.

**The Importance of County Characteristics when Establishing an IHSS Consumer Co-op**

In the process of executing this project, we found that there were other factors about counties which should have driven the selection of sites. The size of the counties clearly seemed to make a difference, in the direction of larger counties more likely to find the co-op beneficial and possible. In those counties which had few IHSS recipients (e.g., Yolo and Sonoma), the impact of adding a new model for IHSS service delivery on the existing system could be felt more; hence there was more resistance from county personnel in smaller counties. Also, the capacity of the county to meet the intermediary service needs of its IHSS population may be related to the number of recipients in the county; that is, it's easier for smaller counties (with smaller number of recipients) to provide intermediary services than for larger counties where several thousand consumers must be served. Consequently, there was a tendency for smaller counties to feel there was no need for the co-op. On the other hand, smaller counties
might be a better site for informal co-op development. Finally, because administrative overhead is built on authorized service hours (which is directly correlated with the number of recipients and the severity of their disability), those counties with larger, more severely impaired IHSS recipients have larger budgets. These larger budgets may allow more flexibility in innovation than in smaller counties.

**Is three years long enough to get the co-op started?**

The development of a co-op can occur more rapidly when key factors are in place. But as in the case of San Diego, even when the climate was right for implementing the co-op, bureaucratic barriers can significantly delay the actual implementation of the concept. While San Diego's co-op development team managed to get county and state commitment to start and fund an IHSS Consumer Co-op in thirty-three months, this same county has been waiting over a year for approval of the waiver request related to the project. This county has since adopted the Public Authority.

Both the history of the Public Authority and our "almost success" in San Diego suggest that three years may not have been sufficient for IHSS Co-op development in California.
The overarching reason co-ops were not embraced in California as a mechanism to ensure maximum consumer involvement in designing and delivering high quality personal assistance services (IHSS) was that the option of co-ops was not available to the principal policy makers and players in California until the late 1990's, long after the policy agenda was shaped for IHSS Public Authorities, which began in the late 1980's. This agenda was set by key self-directed consumer leaders, their advocacy organizations and Service Employees International Union (SEIU) in response to the threat during the early 1990's of "managed care" or "capitated" models of providing and funding services (i.e. the "contract mode"). Significantly, IHSS consumers were deeply involved in shaping the outcome of policy and funding related to the threat of managed care dominance of the IHSS program in California. Essentially, by the time the Co-op Project started in California, the Public Authority had a momentum within the state that, in many respects, an IHSS Consumer Co-op could not compete with.

The Public Authority: An effective solution to Intermediary Services

The Public Authority, as discussed earlier in this report, provides many of the benefits to consumers in the IP mode which the co-op could provide. Consider the snapshot of accomplishments reported by the San Francisco IHSS Public Authority after five years of operation:

- "We run a responsive Central Registry that refers screened independent home care providers (IP's) to consumers.
- We have successfully cultivated an innovative labor-management relationships with Health Care Workers Local 250, SEIU, to the benefit of both consumers and workers
- As a result of our work, San Francisco is the only county where IP's receive significantly more than minimum wage -- $9/hr as of October 1, 1999.
- We initiated, planned and implemented on March 1, 1999, the only comprehensive employer-sponsored health coverage for IP's in the state
- We added dental coverage as an IP job benefit January 1, 2000
- We are an acknowledged leader in plans for improving long term care in San Francisco"

With these and other benefits, general dissatisfaction with the IHSS system (although still present) was at a threshold below that needed to mobilize interest in the co-op.

---

"From "Celebrating 5 Years of Success", a publication of the San Francisco IHSS Public Authority, 2000.

---
CONSUMER ISSUES

A Lull in Consumer Activism Statewide?

Building on California's rich history of consumer activism and understanding the essential roots of co-ops, all pilot sites were encouraged to mobilize consumers and organize local consumer leadership to build consensus for co-op development in the county and to work with IHSS leadership to identify methods to implement the co-op.

Many would argue that the drive behind the long history of consumer-driven change in the IHSS program in California has been sparked by a perception by consumers that something critically important was being threatened—typically a "threat to personal autonomy" or "the loss of services/rights." The history of IHSS in the state of California has been punctuated with many such potential threats to the autonomy of people with disabilities, which has resulted in focused consumer activism, frequently successful. The last major threat of any significant proportion in IHSS, prior to this project was the possibility of National Home Healthcare "taking over" IHSS in California in 1993, and thereby, imposing a medical model (with minimal consumer choice) into the administration of IHSS in counties.

During the pilot in Tulare county, consumers organized a sustained (and eventually successful) rally to keep National Home Healthcare from dominating California's IHSS program. John Wilkins (consumer leader who organized consumers in Tulare), gave us the following paraphrased account21.

Senate Bill 24 went into effect in late 1992. The idea was to test the proposal by National Home Healthcare that they could provide for the needs of all IHSS recipients in counties at lower cost to the state. If successful, the plan was to expand the concept in counties throughout the state.

Almost immediately, things began to go bad and the county began to get complaints from consumers in 1993. Around the middle of 1994, I was invited to attend a meeting of the Public Interest Center in Sacramento run by Tom Porter (long-time community leader for consumer-directed IHSS in California). Later in 1994, I went to Tulare County where I joined ACT advocates, Don and Marilyn Root, to organize a grassroots campaign against National Home Healthcare. Our big problem was the word about National was not getting past the county line (i.e., they were serving the less severely impaired, and lowering recipient's hours. For example, Marilyn Root was getting 6 hrs/day; National cut her to 2 hrs/day).

Tulare was a financially troubled county. National brought in 20 million dollars to bail them out, so the county looked the other way when consumers complained. We took the message (data from an evaluation study conducted by Carol Barnes of the Institute for Social Research at CSU Sacramento) to the public and recruited 300 consumers in Tulare to join us (out of 3600 total recipients in that county).

When the National Home Healthcare contract came up for renewal in 1995, HCFA had come in to pull the funds National provided to Tulare because it violated the requirements of the PCSP (Title XIX) program. This resulted in a vote against renewal.

When invited to receive a project grant to start a co-op in Tulare, John Wilkins (original organizer in Tulare County) stated that he could not currently coordinate sufficient consumer involvement; that his own efforts to mobilize consumers for the independent living center he worked for, were not very successful.

IHSS Recipients have Limited Personal, Tangible, and Social Resources

Depending on the amount of volunteer labor needed for staffing, developing and running a co-op can be labor-intensive. It is potentially harder to achieve when co-op members are people with disabilities because they frequently have limited personal, tangible, and social resources to start something from ground zero and sustain it. Compromised personal resources include fragile health, limited experience starting a business (a co-op is a business). Compromised tangible resources include limited income, limited access to transportation (to attend meetings), and limited IHSS hours to support them in their development work. Social resources which are compromised include potentially limited family, friends, neighbors, to provide supports not available formally. As example, John Wilkins, organizer of the consumer movement in Tulare County, reported that his colleagues Don and Marilyn Route developed serious health problems after their successful bid to return Tulare to an IP county, causing them to retire from the Tulare consumer leadership group.

In our demonstration sites, only two co-op sites continued their work the entire three years of the project. While their individual experiences and the outcome of their efforts were quite different, the importance of strong consumer leadership to launch the co-op is clear.

In Orange County, the co-op was developed by an independent living center, which had a long history of activism and strong reputation in that county. Staffed by individuals with disabilities, this group was able to sustain the involvement of a few consumers for a couple of years, but due to health or personal reasons, or diminishing interest, no sustainable leadership for the co-op effort could be found in the community. This group was not successful in establishing a co-op in Orange County.

In San Diego County, the co-op developer was a university-based disability organization. The co-op concept was marketed to an existing IHSS Consumer Leadership Group, which had a history in San Diego and consisted of community leaders with disabilities. As such, the membership of this group had a significant history prior to the Project, had an existing relationship with County IHSS, and had support from County IHSS for their work. Consequently, this group was sustained throughout the project, and continues still. Moreover, many of them were not just personal assistance service users, but were also employed by various aspects of the system, including representatives from Aging, the Veterans Administration, Independent Living Center, Regional Center, etc. The success of this group to negotiate a contract with San Diego County involving a multi-million dollar commitment from the county and state was a formidable achievement reflecting the undaunting, sophisticated leadership of this group.
The Public Authority: Consumer Voice without Consumer Work

In a state marked by a long history of consumer activism and a strong preference for consumer control, it was assumed that there would be great interest in developing a model for IHSS service delivery that would be more consumer-directed than the Public Authority. However, our experience suggests that, for some, the co-op's promise for more consumer direction came with a demand for consumer time and resources, which many did not have nor want to commit. In theory, the project looked to potential co-op members to design and develop the co-op and negotiate long-term arrangements with the county for sustained support. In contrast, the Public Authority made similar promises of consumer direction and control, without asking consumers to do much in return. The Public Authority's staff was available to take the concerns of consumers and translate them into action. Hence, consumers could have a voice, without having to do the work of creating and implementing solutions.
POOR MARKETING OF THE CO-OP

Disability co-ops are essentially non-existent in the United States. While co-ops are numerous in California, there are no disability co-ops per se in this state. Reflective of this, the Center for Cooperatives at UC Davis, a state-funded program to promote co-op development in California, had no experience with disability co-ops, nor staff with expertise in this type of co-op.

Having no precedent which merged the knowledge and skills of disability issues with co-op enterprise development, this project's co-op development work depended on merging two forms of expertise within two separate systems: co-op and disability. We specifically targeted disability expertise as most essential, assuming that co-op knowledge could be imported through consultation and technical assistance. We deliberately utilized well-established disability agencies to develop the IHSS Consumer Co-op because these agencies fully understood and had experience practicing consumer-driven service delivery. Many of them had majority consumers in leadership and staff positions. It seemed more reasonable to expect a disability organization to learn about co-op structure and apply it to IHSS, than to expect co-op experts to learn the nuances of IHSS and consumer-directed services.

However, our experience suggests that co-op expertise may be more crucial because of the significant marketing that is needed to "convince" people to join something innovative. Whatever the case, somehow having both disability and co-op expertise available to the development effort is without question, should this experiment be tried again.
A Post-Mortem Analysis of the California PAS Consumer Co-op Project

Although unsuccessful in starting consumer co-ops in California, we discovered some interesting findings about the many faces of consumer-direction. A brief discussion follows.

- The Promise of More Consumer-Control was NOT Stronger than the Fear of Losing What Consumers Already Had

In our project, some consumers tended to see their individual welfare jeopardized by joining a collective effort like the co-op. In fact, unlike most individuals who join co-ops, they saw the sharing of their personal resources (i.e., their workers) as a threat to individual welfare, rather than as an opportunity for solving their individual problems collectively (which is the keystone of co-ops). One explanation for this finding may be that adults with disabilities who use IHSS in California, live so close to the margin of having their needs met that, generally speaking, they were not willing to risk what they already had (no matter how imperfect) to try something that was unproven. The promise of consumer-control was not stronger than the fear of jeopardizing what they currently had.

Nerney (1998) eloquently describes the “near absolute impoverishment of individuals within the most costly system of care in the world” (p. 2). He accurately points out the irony of a system which is willing to spend $90,000 a year to care for people with disabilities in institutions, but fails to redirect those dollars to pay for services for those same people who want to live in the community. IHSS is one of those essential services for people with disabilities living in the community. He goes on to describe the pernicious effects of poverty which include isolation from the community, lack of real friendships and relationships, and lack of disposable income. While our findings are based on field observations only, the work of our co-op developers in many counties identified these same conditions which faced the consumers they hoped to recruit for co-op development and participation.

- A Preference for Self-Advocacy over Self-Help?

In our experience, few consumers wanted to join an enterprise like the co-op, which through the operation of a membership-driven business, might come up with solutions to many problems within the IP mode. Co-ops are fundamentally self-help enterprises--people coming together for collective solutions which are not possible as individuals. Inherent to the co-op concept is the active involvement of its members to create and implement these solutions. Involvement may be as little as voting for board members on an annual basis, but can also include contributing volunteer hours to the co-op, or functioning as an officer of the co-op's board of directors. Co-ops are designed to foster the full participation of members through an emphasis on member education. Moreover, most co-ops are grassroots organizations, conceptualized and developed by its members, thereby creating an authentic feeling of ownership of the co-op by its members.
Our inability to recruit consumer interest in the co-op may be related to the self-help nature of co-ops. Although most consumers who were contacted through this project found significant problems with the IHSS system, their interest tended to be on solutions which would "fix the system." Such solutions focused on getting the system to give them more hours, to help them find and train good workers, to pay workers more and provide them with benefits, so competent people would be attracted to the workforce--essentially, to create entities (like the Public Authority) which would meet these needs. This approach reflects more of a "self-advocacy" approach--clearly different from the "self-help" model of consumer co-ops, where solutions to individual needs are crafted through cooperation among a number of people of like situation.

Many times, co-ops provide solutions for members without any major change in the system because solutions through cooperation may merely realign existing resources (e.g., sharing workers for emergency back-up, coordinating jobs for workers which are geographically close to minimize hours spent traveling to new work sites, etc.). Co-ops also have the capacity to shape systems reform, but this is usually accomplished through the collective voice of the co-op, not individual self-advocacy, per se.

- **Why might there be an aversion to the self-help model?**

After many years of the IHSS system expecting consumers to solve its own problems, solutions of a self-help nature may go against the grain of consumers who feel the system has failed and has unfairly placed the burden on recipients. Within this context, the co-op may appear to "let the system off the hook," thereby discouraging consumer interest.

Another disincentive of the self-help model underlying co-ops, is the capacity of people with more severe disabilities to do the "work" of co-op development. While the co-op, in theory, could eventually require minimum involvement of its members, its strength comes from grassroots organization and active participation of its members. The months of discussion and dialogue necessary to conceptualize the co-op requires sustained involvement and interest. Without this, the by-laws which define how the co-op will operate, may not reflect the interests of its members. We described in this report, the numerous health challenges of IHSS recipients which make sustained voluntary activity difficult. Moreover, these health compromises are compounded by the concomitant poverty associated with living in the community on public benefits. Finally, the average IHSS recipient frequently lacks experience in business.

We proposed in this report how the Public Authority meets the needs of IHSS recipients without requiring "work" on the part of recipients--thereby creating a more attractive model of intermediary services than the co-op per se. While speculative, our project raises the question of the viability of self-help models of intermediary services for IHSS recipients. Compromises in the health and personal resources of IHSS recipients carries unique implications for co-op development and ultimately the perceived value of co-ops for this population--in spite of significant advantages which the co-op offers its members, i.e., a structure for ongoing recruitment and education of consumers to participate in a self-determined business, opportunities for full control over how intermediary services are delivered, potentially improving the economic circumstances of members by providing work opportunities through the co-op, and significantly increasing the voice of consumers for systems change.
The global findings of this project suggest that many people with disabilities living in the community on public benefits, may lack the personal resources with which to invest in and start a new business— in spite of the strong attraction a co-op might have for this group. The implications of these tentative findings are discussed below within the framework of social capital.

Is Social Capital a Pre-requisite to the Development of a Consumer Co-op?

Social capital constitutes a force that binds individuals within a society together---into members of a community with shared interests and a shared sense of the common good (Newton, 1997). It is a contextual characteristic which describes patterns of civic engagement, trust, and mutual obligation among persons (Lochner et al., 1999). Networks, norms, and trust that enable participants to act together more effectively to pursue shared objectives (Putnam, 1995).

Social capital theory addresses the issue of "risk-taking" which has been a prominent finding related to consumers in this project. Social capital predisposes citizens to cooperate, trust, understand and empathize with each other—to treat each other as fellow citizens rather than as strangers, competitors or potential enemies (Newton, 1997). Trust and reciprocity are part of the fabric of social capital. Generalized reciprocity is based on the assumption that good turns will be repaid at some unspecified time in the future. As such, it, by definition, involves uncertainty, risk, or vulnerability. It is also based on trust that others will repay the good turn (Kollock, 1994; Luhmann, 1988; Misztal, 1996).

It is undeniable that the co-op depends on similar notions of generalized reciprocity among its members. Yet, our collective experience trying to develop co-ops found consumers contacted in this project did not trust their peers, saw them as competitors rather than fellow citizens (when it came to sharing workers). Is it possible that this lack of trust stems from a compromise in social capital for individuals with disabilities?

Is Social Capital Compromised for Individuals with Disabilities Living in the Community?

Social scientists have argued on many fronts that there is striking evidence that social capital, in America as a whole, has declined over the past several decades. Examples include reductions in the direct engagement in politics and government, church-related groups, school service groups (e.g., PTA's), sports groups, service clubs, volunteer organizations (e.g., boy scouts) (cf., Putnam, 1995 a & b, 1996). That the disability community is merely a thread within this larger fabric of American society, shaped by the same forces leading to the decline of social capital within the nation as a whole, is readily defensible. Moreover, there are unique attributes and circumstances surrounding being disabled and living in the community, which create special zones of risk for compromised social capital. Studies have shown that friendships and meaningful relationships are among the norms of community life.
which are difficult to achieve for many people with disabilities. For those consumers living in congregate housing facilities, social connections are frequently with other people with disabilities (other tenants), paid assistants, and/or the staff of facilities where the individual resides and/or receives services. For those living in neighborhoods, social connections are with the non-disabled community, but attitudinal barriers in neighbors, may slow the process of making meaningful social connections. Beginning and sustaining engagement with the generic community and a well-developed social network requires access to reliable transportation, attendant care, and other supports which may not be readily available. Individuals with disabilities must go to great lengths to get and stay involved in the outside community.

Getting involved may be difficult, but without social connections, there is a predictable erosion in the individual's comfort with uncertainty and risk. Qualitative data, informally collected from IHSS recipients by co-op developers, revealed that the IHSS consumer's tolerance for uncertainty and risk was very limited. That this may be due to significant vulnerabilities experienced living in the community with inadequate supports, is substantiated by the numerous personal anecdotes collected during the course of this project. We learned of consumers being left in bed all day when a worker didn't show up, falling and not being able to get to the phone to call for help for hours, getting sick and needing hospitalization to find their worker gone once discharged, etc. Whether it was one salient negative experience, or multiple episodes of minor atrocities, the result was the same—an erosion of the capacity of IHSS recipients to tolerate uncertainty and risk.

This same perceived sense of vulnerability caused many individuals to protect what they had by refusing to share their workers for the co-op registry, and wanting assurances that the co-op had funding before they would join. For the average IHSS recipient, the margin for survival was so small and tentative that any potential threat to the status quo, no matter how unsatisfactory current conditions were, was not worth the risk.22

Have developments within California's IHSS program led to a passive reliance on the state?

In many ways, current California residents with disabilities are reaping the benefits of a long history of passionate consumer activism. Putnam (1995) argues that the involvement of citizens in representative government is powerfully influenced by civic engagement of a broader kind. He cautions that without appropriate attention to civic engineering which cultivates the engagement of individuals in those affairs which impact their lives, it is possible to develop a passive reliance on the state to solve all problems.

One of the major findings of this work was the discovery that a key attraction of the Public Authority over the IHSS Consumer Co-op might be "consumer voice without consumer work." While this may be appealing from an entitlement point of view, the reflective observer may question whether such an arrangement does not, in fact, cultivate a passive reliance on the state. As example, we heard frequently from consumers during the course of this project that

22 For many IHSS recipients, a breakdown in their management of the IP mode could mean institutionalization.
"things are not good, but they aren't that bad." This was true even in some Public Authority counties. There is a seduction to believing that the Public Authority will remedy all problems. We know too well that even with clear regulatory requirements, there can be a fair amount of variation in how the Public Authority is implemented. Important to this project, there can also be variability in the extent to which consumers truly have a say in how IHSS is administered in their counties.

Few would argue that the independent living movement struggles to develop new leadership, that active passionate involvement of consumers at large is hard to achieve. In many respects, the Public Authority fits this mind-set. That is, the Public Authority will take care of consumer needs with very little effort from the vast majority of consumers in their county. On the one hand, this responsiveness to consumer needs is exactly what many would hope for in a public benefit program. However, at the same time, we question whether, for some segments of the disability population, consumer voice without consumer work is desirable. While we recognize that specific disabling conditions may compromise the level of involvement consumers might have in the IHSS program, we argue that consumer direction without far-reaching consumer involvement is not desirable, in the long run. In this same vein, we question whether a relatively small handful of consumer leaders, no matter how talented and dedicated, truly represent the interests of the entire IHSS population in a county, without a structure for doing outreach to consumers at large and involving them in the selection of these consumer spokespersons.

Within this report we have described the long-term efforts of consumers, advocates, and the labor union to put into place a system for users of IHSS which promotes consumer control over the services received.

The Public Authority represents a culmination of years of effort, yielding a model of intermediary supports long called for by consumers. Yet, in the shadow of such victories, we ask what forms future refinements of the model might take to assure structures which will (1) facilitate active involvement of consumers in shaping better systems of service and (2) identify and cultivate new consumer leadership, representative of the full array of IHSS users. Without active consumer involvement and broad-based consumer leadership representative of constituencies, consumer direction in California's IHSS program may lack authenticity.

Should co-ops for people with disabilities be abandoned?

Co-ops co-existing with the Public Authority: A mechanism for broad-based consumer involvement in IHSS?

In the previous section, we presented an argument that future refinements of the IHSS program should assure more active broad-based consumer involvement in monitoring and shaping service delivery. Inasmuch as AB 1682 mandates the establishment and ongoing involvement of a Consumer Advisory Committee for IHSS within every county, there is likely to be considerable variation in the level of influence this body will have on the IHSS program. Regardless of how counties meet the requirement for establishing an employer of record, almost any entity chosen could contract with an IHSS Co-op for a segment of the population. Consequently, the IHSS Consumer Co-op still has potential value in California.
The co-op, because of its fundamental organizational structure as a member-driven organization, has the capacity to significantly groom consumer involvement. Co-ops are committed to and dedicate resources towards member education, which is essential for participatory governance of the co-op and active consumer involvement in the IHSS program. Governance of the co-op is achieved through the actions of a Board of Directors, who are elected democratically by co-op members. As such, the co-op's Board of Directors consists of consumer leadership, which is truly representative of a broad-based constituency. Co-ops also have a history of and methods for training board members, assuring the grooming and constant renewal of new consumer leaders. The co-op allows the individual voices of members to have greater impact, due to the consolidated voice of the entire membership of the co-op. All of these characteristics go beyond the current requirements for Consumer Advisory Committees in counties. Co-op leadership could sit on the county's Consumer Advisory Committee.

We now pose the question "Can co-ops be a catalyst for building social capital within the disability community?" While the possibilities for IHSS consumer co-ops are still unknown, we propose the value of investing in other types of disability co-ops in California. There are many types of co-ops which may work for people with disabilities, such as housing co-ops, purchasing co-ops (for medical supplies), transportation co-ops, recreation co-ops, etc. Studies show that networks of civic engagement foster sturdy norms of generalized reciprocity and encourage the emergence of social trust (Putnam, 1995). Moreover, they slowly shape a preference for collective benefits, over individual ones, which continues to fuel the strength of the network to negotiate improved political and economic benefits for classes of citizens. Improved political, social, and economic benefits is an overarching goal for people with disabilities; co-ops may provide a structure for achieving these benefits. While this project proposed co-ops as a mechanism for assuring maximal consumer-direction in IHSS service delivery, we conclude that co-op membership of any kind may help people with disabilities to (1) build social connections to the community at large not likely otherwise, (2) develop broader social networks, and (3) eventually develop greater levels of self-sufficiency.

Co-ops can be a structure for building social capital for individuals with disabilities

The engagement of individuals to civic activity (social capital) has been shown to be enormously important to communities and the individuals who live in those communities. Social scientists have unearthed a wide range of empirical evidence in fields such as education, urban poverty, unemployment, the control of crime and drug abuse, and even health, which demonstrates that successful outcomes are more likely in civically engaged communities (cf., applications to sociology (Coleman, 1988, 1990); political science (Putnam, 1993, 1995 a & b), and to public health (Kawachi et al., 1997)).
References


California Department of Social Services. *In-Home Supportive Services Program*. http://www.dss.ca.gov/getinfo/faq/faqprogram


ACKNOWLEDGEMENTS

This project was made possible by a grant from The Robert Wood Johnson Foundation under its national initiative, Independent Choices: Enhancing Consumer Direction for People with Disabilities. Our work was supported through information and technical assistance by staff of the National Program Office at the National Council on the Aging—specifically Jim Firman, Linda Velgouse, Kathleen Cameron, and Pam Nadash. It was the encouragement of staff from this office that led to the writing of this report which captures the lessons learned about the complexities of creating alternative structures for consumer-direction in a state which has a long history of consumer-direction.

Many individuals and organizations contributed to the work presented here. We wish to thank the agencies throughout the state which attempted to create the IHSS Consumer Co-op in their counties. These included the Interwork Institute of San Diego State University, the Dayle McIntosh Center for Independent Living in Orange County, Community Resources for Independence in Napa/Sonoma County, Training Towards Self-Reliance in Sacramento County, and the Marin Center for Independent Living. Their varied experiences are reflected in this report as it illuminates the complexity of establishing consumer co-ops for IHSS users in California. In the cases of the Interwork Institute and the Dayle McIntosh Center for Independent Living, which continued co-op development efforts for the entire project period, this report inadequately reflects the hours of work dedicated by staff and the creative solutions which were developed. We encourage readers to contact these agencies directly for more detailed insights into their achievements and perceptions of critical variables.

Because of the socio-political context of trying to establish IHSS Consumer Co-ops in California, we were dependent on the cooperation of many key stakeholders. For this, we extend grateful acknowledgement to the Department of Adult Services, California Department of Social Services; various independent living centers throughout California; Service Employees International Union, the Public Authority Council of California, Burns Vick and Associates, and the numerous consumers and stakeholders who expressed interest in the Consumer Co-op and/or informed our work. We are grateful to SEIU Local 434B, IHSS Recipients and Providers Sharing (IRAPS), and the Center for Cooperatives at UC Davis for the photos they contributed to this report. We also extend our appreciation to the Center for Cooperatives at the University of California, Davis, which provided the time and co-op expertise of Kim Coontz, in-kind, throughout the life of this project.

Finally, we express our sincere thanks to the numerous consumers and stakeholders who advised our co-op developers in Napa/Sonoma, San Diego, Orange, Sacramento, Marin, and Yolo Counties. While we were not successful in developing the IHSS Consumer Co-op in California, their contribution to this project helped to elucidate why were not able to meet the objectives of this project and creates a platform for greater understanding of the co-op as a vehicle for people with disabilities who wish to have control over their lives and to achieve self-sufficiency.
Economic Facts About California’s Co-ops

Consumer-Owned Businesses

"A Vital Economic Force"

Cooperatives account for over one-third of California’s agricultural product sales

- More than 200 farmer-owned cooperatives operate in California.
- Agricultural cooperatives vary greatly in size. One of the smallest averages $25,000 in annual sales. A few are larger, with as much as $1 billion in annual sales. Most are in between.
- Farmer-owners can successfully compete in today’s global marketplace by marketing their products jointly.