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Personal Assistance Services Cooperatives

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Executive Summary

The Office of Disability Employment Policy (ODEP) asked the Center on Personal Assistance Services (CPAS) to conduct a literature and resource review and identify promising practices and funding sources for consumer-directed personal assistance services (PAS) cooperatives. The primary goal of this investigation was to see how these cooperatives could support PAS, especially to enable individuals to work and find employment.

Our initial literature and resource review suggested that the cooperative model had promise as a method of delivering PAS. However, a closer examination revealed only a few examples of successful consumer-directed PAS cooperatives in the United States. In fact, many were not pure cooperatives, but, rather, organizations with cooperative features. In Europe, on the other hand, there are long-standing models of self-sufficient consumer cooperatives that have been providing service for decades.

We identified five U.S. examples of either cooperatives or groups that had assisted cooperatives, and we talked with people from those cooperatives to learn more about them. Many more PAS cooperatives exist in Europe, but given the focus of this project on U.S. cooperatives, we chose to include only two well-established European cooperatives to see how their experiences may be valuable for people in the United States. The report described seven examples.

- **Partners in Personal Assistance (PPA)** in Ann Arbor, Michigan has been providing PAS services to people with disabilities for more than eight years. With a current membership of 40 consumers and 57 personal assistants (PAs), PPA provides a range of PAS to enable consumers to live independently in their community. PPA's model includes both consumers and PAs in the governance of the organization.
- The **Linking Employment, Abilities & Potential (LEAP) cooperative,** in Ohio, was funded for six years, beginning in 2000. The cooperative established four "pods" (groups of four to nine consumers each), three of which continued to operate after the funding ended. The LEAP cooperative pods provide a way to coordinate and share services for backup and emergencies and to provide peer support to consumers for managing their services. The LEAP cooperative does not administer PAS funds. LEAP now has a grant to replicate the pods in other parts of Ohio.
- The **Tennessee Microboards Association (TMA)** assists in setting up microboards to provide consumer- and family- run services and supports for individuals with disabilities. They define a microboard as a small (micro) group of committed family and friends join together with a person who is vulnerable to create a non-profit organization (board). The microboard is created for the sole support of one individual (or, at most, two related people living together), and it customizes that person's supports to promote empowerment, self-determination, and inclusion. TMA has also assisted in starting cooperatives (which are a form of "macroboard") in Tennessee and Illinois.

- **Bohling Inc.** is a consulting firm that helps to develop human service cooperatives (HSC). In 2004, Bohling Inc. and the Federated HSC created the **Human Services Cooperative of Northern Arizona (HSCONA)** in the Flagstaff region of Northern Arizona, in partnership with The Center for Habilitation. Next, the organization worked to create a second Arizona HSC called **GALA HSC (recently renamed AZA United)**, which was developed to support Latino families and children with autism. The third Arizona HSC to be developed was **Inspire HSC**, which focuses on providing supports to young adults who are in the transition from school to work. Bohling Inc. has also provided consultation to people starting cooperatives in California, Colorado, Illinois, Michigan, New Mexico, and Tennessee.
- **BRINCS (Bridge to Recovery Independent Network South)**, formerly the Michigan Consumer Cooperative (MCC) in Jackson, Michigan, is a consumer-owned cooperative whose membership is comprised of individuals with mental illness and/or developmental disabilities. The cooperative was first started in 2000, but has recently restructured its board to give more control to consumers.
- **The Stockholm Cooperative for Independent Living (STIL)** is a consumer-directed cooperative that was founded by and for people with disabilities in Stockholm, Sweden. Only people who use PAS may become members with voting rights in the cooperative and serve on STIL's board. STIL acts as the employer of record for the PAs, who work directly for the PAS users. Funding for PAS comes from the national Social Insurance fund and is based on the need for PAS rather than means-tested. For more than twenty years, STIL has served as a model to service cooperatives all over the world.
- **ULOBA Cooperative on Personal Assistance**, located in Drammen, is the only PAS cooperative in Norway. It is available to anyone who has a need for PAS, and currently serves more than 700 people across the country. ULOBA is owned by people with disabilities and operated as a non-profit cooperative that serves as the employer of record of the PAs. ULOBA emphasizes peer training of the owners, who then recruit, train, schedule, and supervise their own PAs.

In the consumer-directed cooperatives, ten percent or fewer members are using the cooperatives' PAS services in order to work or to find employment. Employment was not usually a primary goal of the existing PAS cooperatives, because the survival needs of individuals took precedence. Consumers were not able to even think about working, until they had reliable PAS supports in place at home, a phenomenon people called the "progression of PAS." They viewed employment as the "next frontier" for some working age people, with participation in the cooperatives possibly facilitating their moves toward employment. These observations build the case for employment supports to facilitate PAS consumers' moves toward employment. (Depending on the individual's needs, employment supports could include a wide range of different services, such as transportation, housing, job coaches, and modified schedules, as well as PAS.) The people who told us about their cooperatives saw a great deal of potential for the PAS cooperatives to support employment. Nevertheless, they thought it unlikely

that employment would naturally emerge as a major goal of cooperatives, unless it was an explicit focus and goal from the beginning.

We identified the following as advantages of consumer-run PAS cooperatives:

- **Consumers have gained self-confidence and self-determination through participating in the cooperative.** Cooperative members reported becoming more self-sufficient, confident, and able to participate more fully in community life through participation in the cooperative. Among other benefits, they had the right to choose their own workers, which enhanced self-determination.
- **PAS cooperatives focused on workplace PAS could be an essential resource for PAS users who are working or would like to work**. In the existing consumer-directed cooperatives, ten percent or fewer members are using the cooperatives' PAS services in order to work or to find employment. However, people we talked with suggested that PAS cooperatives specifically designed to cover work could be an important resource.
- **Cooperatives are a potential model for delivery under existing programs of consumer-directed care and Medicaid Buy-In services.** People involved in cooperatives stressed that they can serve as viable models for service delivery, especially as more states are introducing consumer-directed care options under Medicaid waivers and participating in Medicaid Buy-In programs.
- **Cooperatives can train people with disabilities to be PAS workers for others in the cooperative**. Some of the cooperatives we talked with have developed training for people with disabilities to provide services to others with disabilities in the cooperatives. This model has the potential to develop job skills and experience and to provide new employment opportunities for people with disabilities.

We identified funding issues for consumer-directed PAS cooperatives:

- **Generating capital or startup funding was the biggest challenge of PAS cooperatives**. Everyone we talked with mentioned startup funding as the major hurdle for consumer-run cooperatives. Costs of liability insurance and delays in reimbursement made it essential for cooperatives to build up adequate funds before initiating services. However, startup costs for consumer-run cooperatives were relatively modest, compared to many service programs. Groups were able to successfully establish cooperatives and cooperative-like organizations with startup funds ranging from $25,000 to $75,000 per year.

We identified a number of funding sources:

- **State Developmental Disabilities Councils were the most frequent sources of startup funding for consumer-directed cooperatives.** U.S. cooperatives and cooperative-like organizations were most likely to get their startup funding from the developmental disability councils in their respective states.

Nevertheless, these cooperatives were not limited to serving only people with developmental disabilities. Once the cooperatives were started, they sought funding under a variety of different waivers and private pay sources to serve cross-disability populations.

- **Private foundations were another source of funding.** Existing cooperatives also received funding from local foundations. This usually occurred after they had received initial funding from other sources, and the foundation funding was sometimes tagged for a specific purpose, such as providing health care for PAS workers. A national foundation—the Robert Wood Johnson Foundation—also funded efforts to start PAS cooperatives in the 1990s, but those efforts were not successful.
- **Centers for Independent Living (CILs) and other disability organizations initiated and provided support for consumer-run PAS cooperatives**. CILs were often the primary initiators or partners in initiating the PAS cooperatives. CILs networked with a variety of organizations, located funding sources, provided staff expertise, and often provided low- or no-cost rent to the PAS cooperatives.

We found that worker cooperatives had other funding sources as well:

- **Consumer-directed cooperatives were not funded by traditional agricultural cooperative sources, but worker cooperatives did tap those sources.** None of the interviewed consumer-directed cooperatives had received funds from the U.S. Department of Agriculture (USDA), but a number of worker cooperatives had obtained startup funding from USDA.
- **Worker cooperatives also utilized workforce development funding to train workers.** The worker-owned cooperatives often relied on private and public workforce development funding to provide extensive programs that trained low-income and unemployed people to become PAS workers. Consumer-run cooperatives have not applied for these funds, in part because their training philosophy is based on consumers training their own PAs. Nevertheless, there may be opportunities for consumer-run cooperatives to seek new funding sources for training workers that are compatible with independent living philosophy.
- **Religious organizations have also emerged as a funding source for worker cooperatives.** In the past few years, worker cooperatives have received funds from both Catholic and Presbyterian organizations to improve the long-term care workforce. Consumer PAS cooperatives may wish to explore partnerships with worker cooperatives or other possibilities for funding from similar organization.

The people at existing cooperatives had many considerations for those contemplating starting consumer-directed cooperatives, including the following suggestions:

- **Cooperatives need time to get established**. The people we talked with generally agreed that starting up a cooperative required at least two years from the first meeting to the beginning of service delivery. At least five to

seven years of startup funding was necessary for cooperatives to have a good chance of becoming self-sustaining.

- **Both large and small cooperatives have advantages.** The ideal size of a cooperative is still an open question. Many who had started consumer cooperatives felt strongly that the small, intimate nature of their cooperatives was the main strength of the programs, creating a sense of community and connection. However, larger consumer PAS cooperatives in European countries and worker PAS cooperatives in the United States have been sustained over decades, suggesting that economies of scale may also provide advantages.
- **PAS cooperatives should seek the required expertise in cooperative structures and service delivery**. On-going and expert technical assistance related to establishing and maintaining a cooperative is absolutely essential. Organizations should take advantage of existing manuals and other resources on PAS. Some of the existing cooperatives have developed resources for their members.
- **Recognize that business-planning expertise is important.** A business plan and expert financial guidance are equally essential. Cooperatives that failed often cited a lack of expertise and experience with business planning as a reason for their failure. Even successful cooperatives wished they had developed business plans much earlier. Cooperatives that serve as financial intermediaries especially need solid business plans, as well as contingency plans for alternative scenarios.
- **Develop alliances with people in government and related programs.** All of the people we talked with agreed that it is essential to know the "players" in state and local government and programs related to PAS. They also agreed that having support from key individuals at the state and local level is critical to success.
- **Base all cooperative-related activities on consumer choice.** Cooperatives should be based on consumer choice. Consumer-directed PAS cooperatives must have mission statements and bylaws that uphold the fundamental rights of consumers to determine their lives and control their services.
- **Recognize workers and consumers as participants in cooperatives**. Promote the cooperative model of both consumers and workers as participants in the cooperative, while retaining independent living principles as primary. One successful cooperative had the stated goal of improving wages and benefits for workers, a goal that has been achieved through offering comprehensive health benefits and higher-than-prevailing wages. In that cooperative, workers are members of the board of directors and have a voice in governance.
- **Examine existing worker cooperatives for solutions to barriers facing consumer cooperatives.** Consumer-run cooperatives may want to look at ways in which worker-run cooperatives have solved these issues.

Introduction

This report discusses and describes current cooperatives that provide personal assistance services (PAS) to people with disabilities. The Office of Disability Employment Policy (ODEP) asked the Center on Personal Assistance Services (CPAS) to conduct a literature and resource review and identify promising practices and funding sources for PAS cooperatives. As requested by ODEP, the report focuses on cooperatives that benefit consumers and provides detailed information about how the cooperatives were started and how they function, their funding sources, and the challenges, benefits, and considerations for others who wish to start PAS cooperatives. A primary goal of this investigation was to see how these cooperatives could support workplace PAS and other PAS in support of employment. However, we found that in existing cooperatives, such PAS employment support was rare. The report includes recommendations that might assist in establishing cooperatives, as well as suggestions for supporting more workplace PAS.

Background Information about Cooperatives and PAS

The International Co-operative Alliance (ICA) broadly defines a cooperative as "an autonomous association of persons united voluntarily to meet their common economic, social, and cultural needs and aspirations through a jointly-owned and democratically-controlled enterprise." [International Cooperative Alliance (ICA), 2006]. Described even more succinctly, a cooperative 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).

The cooperative movement began in the early 19th century in Scotland, to give workers in the cotton mills more opportunity for self-governance, as well as cooperative stores, shared gardening, and access to better education. Cooperatives have grown to include businesses in such diverse areas as agriculture; banking, finance, and insurance; car-sharing; childcare and preschools; economic development; energy; food; funeral and memorial societies; healthcare; housing; purchasing and shared services; and many others. [National Cooperative Business Association (NCBA), 2005]. The International Co-operative Alliance—an independent, non-governmental association that represents 230 cooperatives throughout the world—estimates that 800 million people worldwide are members of cooperatives and that cooperatives employ more than 100 million people (ICA, 2006). In the United States, the NCBA estimates that cooperatives serve 120 million members, or about 4 in 10 Americans (NCBA, 2005).

Although cooperatives are a well-established model with a long history of success, cooperatives to provide PAS are a relatively newer phenomena that began in the 1980s, primarily in the United States and Europe. The impetus to create PAS cooperatives came from two different sources, the desire for empowerment and self-determination among consumers of PAS, and the desire for improved wages, benefits, training, safety, and level of workforce participation among workers in the field of home care.

Method

We reviewed the literature on PAS cooperatives, including both consumer-run and worker-run cooperatives. We conducted Internet searches and also asked people who were knowledgeable about PAS services to identify possible examples of PAS cooperatives. On the basis of the literature and resource review, we created a list of more than 30 examples of consumer- and worker-run PAS cooperatives; about half of these were thought to be currently operating. Following the literature review, ODEP asked us to focus our attention on gathering more detailed descriptions of existing consumer-run PAS cooperatives, rather than worker-run cooperatives. We contacted (or attempted to contact) all of the consumer-run organizations in the United States that had been mentioned in the literature. A number of those had never been started or were no longer in existence. In the United States, we found five examples of either cooperatives or groups that had assisted a few cooperatives, and we talked with people from those cooperatives to learn more about them.

There are many more consumer-run PAS cooperatives in Europe. Since the focus of this project was on U.S. cooperatives, we chose to interview people at two well-established European cooperatives to see how their experiences may be valuable for people in the United States.

For all seven case studies, we spoke with one to four people in the cooperative to learn more about how cooperatives work. We also gathered written information from the Internet. This report is based on conversations with more than twenty people who have been involved with PAS cooperatives, primarily the currently existing cooperatives described in the case studies, but also a few that no longer operate, described in the section on "Lessons learned from other PAS cooperatives."

Organization of the Report

The next section includes seven case examples of consumer-run cooperatives and organizations that have initiated them. The descriptions illustrate how the cooperatives were started, including their histories and missions. They provide information about the structure and governance of the cooperatives, organizations that assisted in the cooperatives' development, and current funding, costs, and other financial issues.

The case studies also include details on the people who are served by consumer-run cooperatives and the kinds of services provided. We describe how the current PAS cooperatives provide workplace PAS, as well as recommendations from the people we talked with about how to expand the role of PAS cooperatives in employment. We describe the characteristics of workers in PAS cooperatives, including information about wages and benefits, and whether the workers themselves have disabilities. Other topics we discuss include training for both consumers and workers, and rights and responsibilities for arranging PAS.

The case examples include information about whether the cooperative has been replicated, including factors that contribute to transferability. Finally, our discussion

summarizes the challenges and benefits of the cooperative, and recommendations for others who are interested in starting consumer-directed PAS cooperatives.

Following the sections that describe existing consumer PAS cooperatives, we discuss lessons learned from other PAS cooperatives. These include consumer-run cooperatives that no longer exist or were not able to get started. We also include information from worker cooperatives that may be helpful to consumers who wish to start cooperatives.

In the final section, we summarize the advantages of consumer PAS cooperatives, current funding of PAS cooperatives, and findings for organizations that are considering starting PAS cooperatives.

Promising Practices Case Studies: Existing Consumer-Directed PAS Cooperatives

The following seven case examples describe currently existing consumer-directed cooperatives in the United States and in Europe.

Partners in Personal Assistance (PPA)

Partners in Personal Assistance (PPA) in Ann Arbor, Michigan, has been providing PAS services to people with disabilities for more than eight years. With a current membership of 40 consumers and 57 PAs, PPA provides a range of PAS to enable consumers to live independently in their community. PPA's model includes both consumers and PAs in the governance of the organization.

History and Mission

In 1996, a small group of people with disabilities and their personal assistants (PAs) began meeting informally in Ann Arbor, Michigan, to discuss alternative ways of providing PAS. Consumers noted difficulties in obtaining and keeping dependable, high-quality personal assistance. Both consumers and PAs agreed on the importance of paying competitive wages and providing decent benefits for workers. The group was dissatisfied with the existing level of services and wanted to empower consumers to direct and manage their PAS so that they could participate in all aspects of community life. Growing out of those meetings, PPA opened its doors, in 1999, as a cooperative based on principles of self-determination and independent living for consumers and better working conditions for PAs. According to their Web site, the mission of PPA is "to create and maintain the highest possible standard of assistive services for people with disabilities, as well as adequate training, wages, and benefits for their personal assistants." Committed to partnership between consumers and PAs, PPA is managed cooperatively, with both consumers and PAs on the board of directors. Many of the founding members are still actively involved.

Structure and Governance

PPA was first incorporated in 1999 as a cooperative. The organization received assistance in setting up the cooperative from Jim Jones, who worked for the Inter-Cooperative Council (ICC) at the University of Michigan, and currently works at NASCO (Northern American Students of Cooperation). Both of these organizations provide consultation primarily to housing cooperatives. At PPA, Jones provided classes in how to set up a cooperative, as well as on-going consultation during the process of becoming a cooperative. However, when PPA applied for 501c3 tax-exempt status in 2002, the Internal Revenue Service suggested that a cooperative serving only its own membership would not qualify as a charitable organization. PPA members agreed that it was important to attain tax-exempt status. (Previously, PPA had used another non-profit as a fiduciary to accept donations on PPA's behalf). PPA members sought legal advice and decided to incorporate as a non-profit with a board of directors; subsequently, PPA has been successful in obtaining tax-exempt status. PPA members also mentioned that the cooperative model required a level of commitment and volunteerism that was more difficult to maintain than a board of directors model. Nevertheless, the founding members and

staff believe strongly that the cooperative model provided essential momentum for PPA. As one of the PPA staff described it, "Despite the problems we have had with tax exempt status, I would say that we would never have gotten off the ground if it hadn't been a coop. The ideal sustains people. We are all working together, and it has to be consumer-driven." The organization maintains a strong commitment to democratic ideals and the involvement of both consumers and workers at all levels of the organization.

The current board of directors includes four consumers, one PA and three community members.

Organizations Involved in Starting and Maintaining PPA
PPA founding members and staff credit a number of organizations and individuals with supporting and nurturing PPA's development, and they acknowledge that it would have been impossible to start and grow PPA without that support.

Jim Jones (affectionately called "Mr. Co-op" by PPA members) provided the training and consultation to set up the cooperative structure at PPA, and he reports that he was actively involved with PPA for about five years. In an interview, Jones praised the "hybrid nature" of PPA in that it involves both PAS consumers and workers. Experienced in establishing housing cooperatives, Jones believes that PAS cooperatives that support both consumers and workers have the strongest potential for long-term success. Although he is accustomed to working with cooperatives as a business model, he found that service-oriented cooperatives, like PPA, generally seem to require a grant base for startup.

The Washtenaw Association for Community Advocacy (WACA) was another organization that played a key role in establishing PPA. Staff and members at PPA described WACA's director at the time as "one of our biggest cheerleaders." His knowledge of policies, programs, and legislation related to PAS—developed on the Long Term Care Task Force and after many years of working for non-profit organizations—helped PPA to navigate the process of establishing itself as an organization and negotiating contracts with funders. In the early years, WACA also served as a fiduciary organization for contracts and donations.

PPA members and staff mentioned the support of the Ann Arbor Area Community Foundation, which provided startup funding for health care insurance for the workers, as well as a generous grant from the Michigan Department of Community Health. In addition, PPA paid reduced rent at the NEW (Nonprofit Enterprise at Work) Center, an incubator building that was established by the McKinley Foundation to support new small businesses and non-profits.

PPA also works closely with the Ann Arbor Center for Independent Living (AACIL), and the two organizations have provided mutual support over the years. AACIL provides a wide array of services to consumers and referrals to PPA. Some PPA consumers and a number of the PAs work at AACIL. The two organizations also conduct joint fundraising efforts. PPA participates in an annual fundraiser put on by AACIL that benefits both groups.

PPA staff and members reported that labor unions were not active in organizing PAS workers at the time PPA was beginning. The Service Employees International Union (SEIU) is currently involved with the Michigan Quality Community Care Council (MQC3), which is developing a statewide registry for independent providers. SEIU has recently approached PPA about possible collaboration.

Current Funding, Costs, and other Financial Issues
PPA currently receives pass-through Medicaid monies through the Washtenaw Community Health Organization (WCHO) at the Department of Human Services, and My Choice Medicaid Waiver monies through the Area Agency on Aging. Washtenaw County School District funds PAS services for two members who are under 18 years. PPA also bills private pay sources, such as an automobile insurance company, when a consumer is authorized for services through that insurance. In general, the process works as follows: A consumer is authorized for services by one of the funding sources. PPA provides the services and pays workers twice a month. At the end of each month, PPA bills the funding source. Each source has different agreements about how quickly the bills will be paid, generally ranging from 30 to 60 days. However, staff report that payment of bills sometimes takes 90 days or longer, creating cash flow problems for PPA. The issue of slow payment of bills is not unique to PPA, but presents particular challenges for a small organization without large cash reserves. PPA reports that private pay sources have been generally more flexible, pay more quickly, and have sometimes approved higher wage rates for PAS workers.

PPA generally bills at the rate of $14.50 per hour and the workers are paid $9.40. The margin of $5.10 per hour covers all of the administrative costs, including the bookkeeper, administrative coordinator, and clerical salaries, training for workers and consumers, rent, insurance, legal consultation, and other overhead. PPA is currently trying to accumulate more reserve funds to handle cash flow issues. PPA is also seeking more grant funding to afford more training for consumers and workers.

From the perspective of Jones, PAS cooperatives could be capitalized as businesses, but he found that people who were receiving PAS services were less familiar with business models and, perhaps, less willing to take business-related risks for fear of losing those services. He believed that capitalizing a PAS cooperative such as PPA was the biggest hurdle, and he mentioned on-going cash flow problems, often due to delayed payments by the organizations that are contracting the services, as another major barrier. For those reasons, he believed that establishing a grant base for start-up was important, and he thought that organizations providing PAS services could be attractive to foundations and other non-profit organizations.

Consumers
Currently, 40 consumer employers receive PAS services from PPA; the number has varied between 35 and 45 over the past few years. Almost all consumers have physical disabilities. Currently, 20% have cognitive/intellectual disabilities (8 of 40), but they generally have multiple disabilities that include physical disabilities. Sensory and mental health disabilities are rare; usually they are conditions that are secondary to a physical disability. More than half (58%) of the consumers are

women (23 of 40). Eighty percent of PPA consumers are between the ages of 18 and 64 years (32 of 40); there are two consumers under 18 years and six consumers 65 years or older. PPA staff estimate that the average age of consumers is about 42 years. About 95% of consumer employers are white (38 of 40); one is African American and one is Latino/Hispanic.

What the Cooperative Provides
PPA provides a range of services, including assistance with activities of daily living (such as eating, dressing, and bathing); instrumental activities of daily living (such as preparing meals, shopping, and housework); other personal care, stretching and range of motion assistance; as well as assisting consumers to participate in recreational outings, meetings, conferences, and other events.

In order to receive PPA services, consumers must have a source of funding for the services. About 95% of PPA consumers receive funding from Medicaid, which comes through different organizations, depending on the type of waiver. Other sources include school district funding and private insurance.

At this time, PPA provides about 4,000 hours of PAS services per month for the 40 consumers who receive services; the average is about 100 hours per month per person. However, the number of service hours varies greatly by person, depending on the disability and the number of hours authorized by the funding source.

PAS in support of employment. Members of PPA believe that employment is an important aspect of community life that PAS can support, but the goal of employment is not a large emphasis of the cooperative. Currently, 4 of the 40 consumers who receive PPA services (10%) are employed. Two are working in the local center for independent living as advocates, and another works as a private consultant on disability issues. The other consumer works in a restaurant, clearing tables. In the past, consumers have also worked in retail jobs. Some consumers have obtained employment-related experience by working for the cooperative, including administrative, clerical, and non-profit-board-related experience.

At work, PAs generally provide work-task related assistance with manipulating papers, books, and other materials, and other clerical tasks. They provide personal care task assistance with eating, or using the restroom, as needed. They may also provide transportation.

Who provides services? At this time, 57 PAs provide services to the consumers of PPA. More than 80% are women (46 of 57). They are all between the ages of 18 and 64 years, with the average age estimated at about 30 years. About three-quarters of the PAs are white (74%; 42 of 57); more than twenty percent are African or African American (21%; 12 of 57); two are Latino/Hispanic, and one is Native American.

Some of the PAS providers themselves have disabilities. One has Asperger's Syndrome, and four have physical disabilities, such as mobility limitations due to illness or injuries that were not work-related. PPA staff knew of two work-related injuries at PPA that were handled through Workers' Compensation, including a

back injury and a hernia. PPA provides training to all workers to help prevent injuries or secondary conditions (described in more detail below).

PPA staff reported that about one-third of the PAs are family members or friends of the consumers for whom they work. PPA strongly supports the idea that family members should be paid for providing PAS, if the consumer chooses that arrangement.

According to PPA staff, PAs must be able to take direction and to read and write. PPA conducts a criminal background check and checks applicants' references. Currently, there is no certified home health training in the Ann Arbor area, but PPA is working with the community college to develop a training certification for PAs.

Wages and benefits. PPA currently pays workers at a rate of $9.40 per hour. PPA staff report that agencies in the areas currently pay $8.15 per hour. They also note that in Michigan, independent providers work for $6.50 and receive no training or health care. At this time, the MQC3 is developing a statewide registry for independent providers that will provide some screening and training of workers, but the pay rates will remain much lower than those of PPA. PPA also pays workers twice a month, noting that this is especially important for people working in relatively low-paid jobs. In addition, all PAs who have worked at least 30 hours per week for 90 days are eligible for HMO health care. PPA pays 65% of the premium and the workers pay the remaining 35%. Workers are also eligible for affordable vision, dental, and disability insurance through PPA.

Training. For consumers, PPA provides consultation with PPA staff and peers on how to manage their PAS. Consumers are assisted in developing a manual for their PAs that includes a job description, emergency plan, description of specific health problems needing monitoring, work policies, disciplinary steps to deal with violations of work policies, evaluation forms, and other essential materials.

PPA also provides training for PAs, including the following classes:

- CPR and 1st Aid (*mandatory*)
- Universal Precautions/Health Issues (*mandatory*)
- Lifting and Transferring Safely

PPA is also in the process of developing the following classes for PAs:

- Working with People with Disabilities
- Advanced PA Skills (Bowel/Bladder Management, Range of Motion Exercises)
- Independent Living Recipient Rights
- Body Mechanics

Much of the training takes place one-on-one, with the consumer training the PA according to the particular ways that he or she prefers to be assisted. PPA would like to offer more joint training for consumers and PAs, including a class called, "Communication Skills and Conflict Resolution," but the logistics of paying PAs to

attend the training and, at the same time, covering the backup needs for PAS have proved difficult.

Arranging for services: Rights and responsibilities. PPA recruits, screens, and trains the PAs. When a consumer joins PPA, the organization sends one to three PAs who might be "a good fit" for that consumer. The consumer chooses and directly supervises the PA. The model used by PPA would not be a good match for a consumer who wanted an agency to "just send a worker." Active self-determination by the consumer is integral to the process. In cases where consumers with cognitive/intellectual disabilities have limitations in their ability to supervise the PA, the consumer chooses a friend or family member as an advocate to assist with supervision. PPA emphasizes that the consumer is the "person in charge," rather than the PA.

PAS users set their own schedules with their individual providers, although they may consult with PPA to coordinate the availability of PAs. The consumer is responsible for arranging backup assistance when the regular PA is not available, and PPA encourages consumers to establish relationships with more than one PA for backup.

Transferability

The PPA model has been extended, on a very small scale, to other parts of Michigan through arrangements that PPA calls "satellites." These arrangements evolved when consumers in other areas contacted PPA for recommendations of PAs in their areas. In some cases, PPA knew of good PAs in those areas and helped the consumers and the PAs connect. Once the relationship was established, the billing for PAS services could go through PPA. But the "satellite" model only works if both the consumer and the PA receive some orientation and training and make a commitment to the PPA model. There are currently two consumers who are receiving "satellite" services, and there have been other such arrangements over the years.

Challenges, Benefits, and Recommendations

Lengthy set-up time. All of the PPA members, staff, and consultants we interviewed emphasized that it took a long time to create and establish PPA. A small group of founding members met for about three years before they were ready to create the organization, and it took even longer before the organization was securely established and operating smoothly. As one staff member described it, "It probably took another six years from when we filed DBA, before we got the big glitches out."

Training was another identified challenge. PPA is committed to training both consumers and PAs, but large training sessions present financial and logistical challenges. There is little extra money to pay for training at all, and it is difficult to arrange backup PAS when the PAs are being trained together. PPA members and staff hope to obtain grant money to cover this cost.

Recruitment and scheduling of PAs were also mentioned as challenges for PPA. In order to attract and keep good PAs, the organization must provide them with enough hours of work. The administrative coordinator noted that at times there are PAs who need more work and consumers who need more PAS, but scheduling

conflicts make it hard to meet all the needs. The high price of gas has also made it more costly for PAs to travel from consumer to consumer, especially when consumers are authorized for only a small number of hours of service at a time. Although consumers schedule their own hours, PPA staff must keep track of all the schedules, and they are looking for more sophisticated scheduling software to assist in that process.

Financial and time commitment. The cooperative model required a level of financial and time commitment that many people involved with PPA found difficult to make. PPA staff and members noted that they had learned about worker-run PAS cooperatives in which members paid $500 to join, a sum that seemed impossible for most PPA members. Even PPA's initial fee of $25 was a hardship for some consumers. One of the founding members, Jody Burton Slowins, also noted that by the time PPA decided to incorporate as a non-profit with a board of directors, the organization was essentially operating like a directorate, with a small number of people doing the work, rather than as a cooperative. As she put it, "The biggest challenge is getting active involvement." She notes that people with disabilities may have some physical limitations that affect the amount of energy they can devote to an organization, and it is important for PAS cooperatives to take that into account.

Board member involvement. Another challenge was getting people to be involved as board members. PPA will benefit from a group called "Board Connect" that is located in the building where PPA is housed. Board Connect works with companies and organizations in the area, encouraging employees to become involved by sitting on boards and making a financial commitment to the organization.
Despite the many challenges, all of the members, staff, and consultants we interviewed at PPA were extremely enthusiastic about the organization and its benefits. PPA has been able to establish itself as a self-sufficient non-profit organization that delivers services to people with disabilities and provides decent wages and benefits to workers. Asked about advice for others who are trying to start PAS cooperatives, Burton Slowins suggested, "Find someone who really understands cooperatives and how that kind of organization and structure works. It is good to have people who are big fans and know how to get things done. Learn as much as you can about setting up, before you dive into it." Other staff also emphasized the importance of developing a business plan early on, a recommendation that was echoed by the consultant.

Linking Employment, Abilities & Potential (LEAP) PAS Cooperative

The Linking Employment, Abilities & Potential (LEAP) cooperative was funded for six years, beginning in 2000. The cooperative established four "pods" (groups of four to nine consumers each), three of which continue to operate after the funding ended. The LEAP cooperative pods provide a way to coordinate and share services for backup and emergencies and provide peer support to consumers for managing their services. The LEAP cooperative does not administer PAS funds. Consumers have their own funding sources (primarily Medicaid) and receive services through a variety of local agencies and independent contractors. Consumers in the pod agree to share PAs for backup, emergencies, and accessing their community. Hours are billed to the consumer who uses them. LEAP and the pods have worked out reciprocity agreements with agencies in the area so that agencies will pay a PA that is not the consumer's regular PA when the consumer uses backup PAS through the pod. In practice, however, PAs have often volunteered to assist a consumer in the pod, especially when services are needed on an emergency basis, so that no funding was even needed. That kind of informal sharing grows out of close personal ties between consumers and PAs who participate in the pods. LEAP now has a grant to replicate the pods in other parts of Ohio.

History and Mission

Beginning in 1993, a statewide Personal Assistance Coalition was formed in Ohio to proactively address PAS issues. The coalition included PAS users, family members, centers for independent living (CIL) and other advocacy organizations, service providers, funders, and representatives of government agencies. The coalition had 3 goals: 1) to identify current PAS resources and services; 2) to create a vision statement about what was needed; and 3) to develop an action plan to implement the vision. One recommendation was to develop a community-based consumer-directed PAS cooperative as a way of expanding consumer-controlled options.

As a result of that recommendation, the Ohio Developmental Disabilities Council (Ohio DD Council) put out a Request for Proposal (RFP) to create consumer-directed PAS cooperatives. In 2000, the Ohio DD Council funded the LEAP CIL to create a PAS cooperative in Cleveland, Ohio. LEAP received funding for six years and has recently obtained a replication grant from the Ohio DD Council to assist other organizations in establishing PAS cooperatives in other parts of the state. LEAP is one of ten CILs in Ohio, and the independent living philosophy has always been integral to the cooperative.

At LEAP, a consumer-directed cooperative planning committee made up of consumers, parents, consumer advocates, and professionals, met quarterly for decision-making. The planning committee prepared the mission statement that has guided the development and implementation of the coop:

> To provide a consumer-controlled, cooperative system for the purpose of providing individuals with disabilities such personal assistance as will allow them to live as independently as they choose in whatever environment they choose to live.

During the first year of funding, the project director and others on the team visited and learned about existing PAS cooperatives to explore possible models. LEAP originally proposed a PAS cooperative that would be owned and operated by ten people with disabilities and would serve as a fiscal agent to administer funds in a manner similar to a home health agency. However, the model that evolved at LEAP was a "pod" concept that grew out of asking many consumers what would be most helpful to them. A pod is a group of four to nine consumers who share their PAS resources. Neither LEAP nor the pods administer any PAS funds. Consumers receive services through local agencies and private providers and have their own funding sources, primarily Medicaid. Consumers in the pod share PAs for backup and emergencies, and the hours are billed to the consumer who uses them. In practice, however, PAs often volunteer to provide back up PAS, especially in cases of emergency.

Each pod elects a cooperative coordinator who is the main liaison with LEAP and assists consumers in scheduling back-up PAS and troubleshooting other issues. At LEAP, pods are based on geographic proximity, but they could be formed for other reasons, such as a shared work environment.

Structure and Governance
The program director, Kathy Foley, explained that the concept of a pod is so simple that people often dismiss it at first. But she stated that the small informal nature of the pod is the main strength of the program. A group of consumers who want to share PAS services can form a pod and LEAP provides consultation, training, and support. In order to participate in the pod, consumers must be people who need PAS and:

1. are able to direct their own care (a legal representative is possible for those who are unable to direct their own care)
2. have a funding source (such as Medicaid, insurance, or private pay)
3. have willingness to work and function as part of a small group

The structure is "bottom up" rather than the "top down." There is very little bureaucracy, as consumers in the pods have resisted using forms or having formal rules. There is no board of directors. LEAP has developed a question and answer document that provides guidelines on how the pods operate (LEAP, 2007).

Organizations Involved in Starting and Maintaining the LEAP Cooperative
The Ohio DD Council funded the LEAP cooperative with $25K per year over six years and has recently awarded LEAP a grant of $15K per year to replicate the cooperative in other parts of Ohio. (The replication strategy is discussed in more detail under "Transferability," below.) In starting the cooperative, the LEAP CIL has provided financial resources over and above the grant monies, although it is impossible for the program director to determine a dollar amount.
A key factor in starting the cooperative was extensive consultation with a great variety of different organizations. These included: local consumer advocacy groups; individual consumers with disabilities; Medicaid waiver entities; social services organizations serving people with disabilities, seniors, families and children, and others; a labor union (SEIU); local foundations and boards; and others. There were

some agencies that surprised the program director for their lack of involvement and interest. For example, one local organization never made any referrals to the cooperative despite persistent, friendly attempts to involve them and despite the fact that they served people who clearly could have benefited from the cooperative. But this behavior was the exception, and most local organizations strongly supported the cooperative.

The home health agencies felt threatened at first, but later became allies. The program director had attended Systems Change conferences sponsored by the Centers for Medicaid and Medicare Systems (CMS) and was able to talk with the home health agencies about the fact that consumer direction was being instituted in Ohio and would be affecting their agencies. She presented the cooperative as one way for the home health agencies to become involved with consumer direction at the ground level. The program director believes that it is essential in starting a cooperative like this one, to understand the perspective of home health agencies and involve them as partners.

Current Funding, Costs, and Other Financial Issues
The LEAP cooperative is different from other cooperatives in that it does not serve as an intermediary for PAS funds. The organization had originally proposed to become a fiscal intermediary. Early in the process, however, after consultation with individual consumers and advocacy groups and visits to existing cooperatives, the program director and consumer-directed planning group decided that LEAP would not play a fiscal intermediary role. After the program director and the planning committee had evolved the basic concept of the pods, based on consumer input, they spoke with people from Medicaid agencies to better understand the waivers in Ohio and to discuss their proposal and how it could work under the rules. Medicaid agency people made helpful suggestions on how to slightly modify the concept to make it more workable. However, LEAP saw the project as an opportunity to empower consumers and emphasized that it was important that Medicaid agencies and staff not be in any kind of decision-making capacity. The program director also suggested that staying out of the role of fiscal intermediary may even create enhanced opportunities to advocate for better Medicaid policies and services as an advocacy organization that is not administering such funds.

LEAP and the pods have worked out agreements with agencies in the area so that agencies will pay for a PA that is not the consumer's regular PA when the consumer uses backup PAS through the pod. For example, if a consumer uses a PA in the pod because the consumer's regular PA is not available, the consumer's home health agency will pay the PA, even though that PA was not on the agency's regular rolls.

Consumers
Over the six years that the cooperative was funded, about 60 consumers were involved. At the end of the grant, there were about 30 consumers in four pods, and three of these pods have continued to operate independently since the grant funding ended. Although the Developmental Disabilities Council funded the cooperative, services are not restricted to people with developmental disabilities. All of the consumers have physical disabilities, including mobility impairments, and conditions such as multiple sclerosis, rheumatoid arthritis, cerebral palsy, and

others. Some of the consumers have other disabilities as secondary conditions, but all have physical disabilities. About 90% of consumers are women. About three-quarters are between the ages of 18 and 65 years, and about one-quarter are 65 years or older. None are under 18 years. The average age is estimated at about 40 years. About half of consumers are white and about half are African American.

What the Cooperative Provides

The majority of the pod members use PAS every day, which they receive from their regular providers. Most of the regular providers participate in the pod, which means that other consumers in the pod can use them, by mutual agreement. When a consumer uses a PA through the pod, the service hours are billed to the agency of the consumer that uses the services. The LEAP cooperative pods provide a way to coordinate and share services for backup and emergencies and provide peer support to consumers for managing their services. Most pod members expressed a need for reliable backup PAS as their primary reason for joining the pod: backup PAS is the main function of the pods. Others use the pods for additional PAS for periodic needs, such as attending sporting events or movies, allowing greater community access. Other pod members required only small amount of PAS that they were able to obtain through membership in the pod. For example, one older woman needed housekeeping only every other week and had not been able to find reliable PAs to provide such a small amount of service through other programs. For her, money was not the barrier, as she was able to pay independently for the service. The pod allowed her find trustworthy PAs that had worked for others in the pod.

There have also been times when the pod stepped in to provide much more extensive services for a short period. For example, with the support of the pod, one consumer found the courage to fire her abusive PA. Consumers and PAs in the pod came together voluntarily to provide her daily PAS until she could hire a new regular PA. This situation demonstrates how the pod can function as a safety net and emergency backup for consumers.

PAS in support of employment. During the six years that the cooperative was funded, only three consumers had jobs. Two had full-time employment, one as an administrator in education, and one as an independent living specialist. Another worked part-time as a training consultant at LEAP. Other consumers worked as volunteers, and there were also retired people who had previously worked.

As an organization, LEAP emphasizes employment as a very important part of independent living. Program director Foley, who has a background in vocational rehabilitation, was somewhat surprised that employment did not emerge as a goal for more members of the cooperative. However, she pointed out that many consumers must first become comfortable with the idea of using PAS services to get out into the community, and only later might consider employment as a goal. The LEAP pods provided reliable backup services and peer support that enabled members to participate more actively in their communities. Over time, the self-confidence that comes with belonging to a supportive group and managing one's own services may open up the possibility of work for these consumers. Foley also pointed out that Medicaid funded consumer-directed PAS is starting shortly in Ohio, which will create additional opportunities for cooperatives and work-related

assistance. Ohio recently received a federal Money Follows the Person grant and has recently enacted Medicaid Buy-In legislation, all of which create opportunities.

Although use of the cooperative for employment was rare, there were examples of the pods providing services that enabled people to work. For instance, one of the pod members, a full-time administrator, works in a different area than she lives. She hired a PAS provider from the pod that is close to her workplace to help with a half-hour of personal care needs during her lunch break. This illustrates how the pods can provide flexible scheduling and handle geographical issues related to where people live and work. People with disabilities who work across town from where they live and do not have easy access to the regular PA they use at home can use pod resources at work when task needs are brief or periodic. Foley also noted that this was a potential area that could be developed further in a coop that was focused on employment. For example, shared PAs could provide personal care services at lunchtime or breaks at a number of different worksites that were geographically close.

Who provides services? Over the first six years of the LEAP cooperative, about 40 PAs participated. There are currently about 15 PAs working for people in the pods. Almost all of the PAs are women; there is currently one man working as a PA. All of the PAs are between the ages of 18 and 64 years. About half of the PAs are white and about half are African American.

Foley thought that none of the current PAs working in the cooperative had disabilities that had been disclosed, and she had not heard about any work-related injuries. At LEAP, Foley also runs a training program for people with disabilities that trains and assists them in working as PAs. The program was started to train people with mental retardation to become PAs, and has expanded to include people who have mental health disabilities, people who are deaf or hard of hearing, and people with dual diagnoses, such as both learning and mental health disabilities. One important aspect of this LEAP training program is that it provides support to both the PAs with disabilities and their employers, including consultations and mediations for as long as they are needed, even many years after the initial placement. Foley, who directs both programs, thought there would be more crossover between the cooperative and the training program, but people in the cooperative usually came with their own PAs, and, therefore, had little need to hire PAs from the training program. However, at least one consumer in the cooperative has hired a trainee, and that arrangement worked out well.

Currently, one consumer in the cooperative uses a family member as a PA, and that family member is part of the pod. Whether a family member or friend can provide PAS services depends on the type of funding and the rules of that particular funder.

Some of the PAs are State Tested Nursing Assistants (STNA), which is the Ohio equivalent of Certified Nursing Assistants (CNA). However, to participate in a pod, the main requirements are that the consumers in that pod would like the PA to provide services and that the PA would like to participate. Foley described situations in which some PAs wanted to participate in the pods, but the consumers

did not want them. In some cases, she thought that a PA's interpersonal style was too aggressive, leading the group to decide against that PA's participation.

Wages and benefits. The LEAP cooperative is not involved in paying PAs and, therefore, has no direct influence on wages and benefits. In Ohio, PAs generally make $8–11 per hour. However, the cooperative has brought together groups of consumers and PAs in a way that encourages mutual support. Not only have PAs volunteered to assist consumers in emergencies, but consumers have also advocated for better wages and benefits for PAs. LEAP has also been in touch with the Service Employees International Union (SEIU) as a possible alliance to help advocate for better wages and benefits for PAs in general. Nevertheless, to date, that union has been involved only with organizing aides in institutions and has not yet organized home care providers in the Cleveland area.

Training. As part of orientation to the cooperative, LEAP has trained consumers and PAs about consumer direction and control. This orientation includes training on self-determination, IL philosophy, the cooperative system, policies, procedures, responsibilities, and expectations. LEAP staff had originally planned to provide separate orientation trainings for consumers and PAs, but consumers insisted on joint training, and the program director reports that the joint training has worked well. The LEAP cooperative members also use a manual, *Taking Charge: A Hands-On Guide to PAS,* which was developed by the project and Ohio DD Council (Ohio Developmental Disabilities Council, 2005).

The cooperative coordinators, together with all the consumers in the pod, determine what kinds of additional training are needed, and these are often arranged on an individual basis. Much of the training has focused on leadership skill building, such as developing managerial skills, problem solving, and communication skills. Staff at the LEAP CIL have provided training and assisted consumers in finding other resources as needed.

Arranging for services: Rights and responsibilities. Members of the pod are each responsible for hiring their own individual PAs, using their own funding sources, and each pod member directs his or her own care. The pod provides a built-in support system and resources for troubleshooting PAS issues. Members of the pod share their PAS resources in the pod and determine as a group how many PAs are needed to maintain functioning of the pod. Members of each pod work together to hire, dismiss, and schedule the PAs in the pod, as well as to resolve any issues that affect the smooth running of the coop.

New members can bring their own PAs into the pod as long as the PA agrees to participate and the other members of the pod approve. Only the pod as a whole can dismiss a PA from the pod, although individual members have discretion about which PAs they use from the pod. LEAP has developed a Question and Answer document that describes roles within the cooperative and provides a process for how to handle problems and suggestions for trying to resolve issues before bringing them to the pod as a whole (LEAP, 2007).

Transferability
As noted earlier, the Ohio DD Council recently funded LEAP to provide technical assistance to organizations in other parts of Ohio to start cooperatives based on the LEAP pod model. To date, the program director has met with staff from two CILs that are interested in being "host agencies" for cooperatives in their areas. Foley emphasizes that this model works best in an organization that is willing to partner with other organizations and work with multiple funding streams for funding the PAS. A volunteer core of involved consumers, family members and PAs is another requisite for success.

Challenges, Benefits, and Recommendations
The cooperative overcame a number of challenges, some of which became benefits of the project. For example, home health agencies presented a barrier at first, but became more cooperative as they got involved with the project and learned more about consumer direction. In fact, LEAP was able to create agreements with local home health agencies to pay for backup and emergency services that were delivered by another PA in the cooperative.
Another challenge was dealing with consumers' fears that they might lose benefits that they already had. At first, the idea of sharing resources brought up fears that they would lose something. ("What if I bring my PA into the pod and she goes to work for another consumer full-time?") But as consumers began to share resources and trust each other and the group of PAs, they became more willing to take risks.

Consumer gains in self-confidence and self-determination are a benefit of the LEAP cooperative. For example, one consumer who did not leave the house before joining the pod is now planning a vacation to the Caribbean with another consumer and a shared PA!

Empowerment. LEAP has nurtured the development of the pods, but staff always keep in mind that the project is about what the consumers want and not what LEAP wants for them. This empowerment approach has resulted in pods that are now self-sufficient after the grant has ended. LEAP is still a resource for them, but they have the internal momentum to keep functioning without LEAP's involvement.

Involvement of the PAs. LEAP staff and consumers were committed to consumer-controlled services and also learned that involvement of the PAs is vital. For example, when it became clear that one consumer had an abusive PA, it was a group of PAs, along with two of the other consumers, who took the lead in arranging for backup care so that the consumer could feel free to fire the abusive assistant. These PAs volunteered their time to assist in this situation. PAs have also played an important role in helping the consumers become more self-reliant, by encouraging and "cheerleading." ("You can make that decision. Look how far you've come. Don't sell yourself short!")

Personal relationships. The LEAP project director stressed that the close personal relationships within the pods are a key factor in their success. As she put it, "Part of the value of the pod is that it is small and intimate. The consumers and the PAs really care about each other and that facilitates communication. It's not an indifferent bureaucracy, it's a community."

Startup grant funding. In terms of recommendations for people starting cooperatives, the project director stated that finding startup funding is the first big hurdle. LEAP obtained startup grant funding of $25K per year for six years to start the cooperative, and it is now self-sufficient. The program director encourages others to use this model, noting that it is relatively inexpensive and that modest startup funding should be fairly easy to obtain. Of course, this model requires that consumers bring their own source of funding and work with existing agencies to obtain their PAS.

Relationships with other organizations. It is also important to involve a wide range of community partners and relationships with many organizations. Foley recommends seeking out the people who oversee Medicaid funding to ensure that the approach fits within the Medicaid waivers in that state. She noted that it is important to network with all kinds of different organizations, not just the CIL's traditional disability base. She recommended, for example, bringing in agencies that serve older people and those that serve families and children. The project director also talked with labor unions, and she emphasized that it is important to include discussions with labor unions that are organizing home health workers when initiating a cooperative.

Employment. Although few people in the LEAP cooperative used the pods for work, Foley noted that employment may be the "next frontier" for some working-age people who use PAS. She stated that participation in this kind of informal pod may help in a "progression of PAS." Once people are established and secure with their PAS services at home, they may be ready to try employment. However, she emphasized that a PAS cooperative project that focused specifically on work and employment supports would be the best way to foster workplace PAS.

Tennessee Microboards Association (Freedom Co-op Inc. and Other Cooperatives)

The Tennessee Microboards Association (TMA) assists in setting up microboards to provide consumer- and family- run services and supports for individuals with disabilities. The TMA Web site explains that "a microboard is formed when a small (micro) group of committed family and friends join together with a person who is vulnerable to create a non-profit organization (board)." The microboard is created for the sole support of one individual (or, at most, two related people living together), and it customizes that person's supports to promote empowerment, self-determination, and inclusion.

The TMA became involved with PAS cooperatives when a group of people in Memphis wanted to create microboards with overlapping members to support multiple people with disabilities. Advised that serving on more than one microboard is not a good idea, given the large time commitment, the group evolved the idea of a "macroboard," or cooperative in which people could share PAS services. (The cooperative does not preclude people also having microboards.) Consumers and family members, with assistance from the TMA, Bohling Inc., and the Memphis Center for Independent Living (Memphis CIL) developed a proposal for a cooperative based on that idea of a macroboard—a non-profit organization that serves more then one person with a disability. As a result of that proposal, the group has recently received a grant from the Tennessee Council on Developmental Disabilities to establish a PAS cooperative, Freedom Co-op Inc., at the Memphis CIL, beginning in late 2007. Although the cooperative is not yet in operation, it is included as an example of an interrelationship between microboards and PAS cooperatives. The Tennessee Microboard Association's experiences with microboards also have implications for PAS cooperatives, in terms of the steps necessary to establish these kinds of organizations and the possibilities for promoting employment.

We present a section describing TMA and the microboards, followed by a section on the planning efforts to establish Freedom Co-op Inc. in Memphis, and other related cooperatives.

History and Mission of TMA

TMA was started in 2000 by people with disabilities and family members to assist in setting up microboards for the benefit of individuals with disabilities. TMA is based on the model of the Vela Microboards Association in Canada, which originated the concept. Its Web site describes the mission of TMA as follows:

> Our mission is to promote the creation of microboards for individuals with disabilities in keeping with the principles of self-determination, freedom, authority, and responsibility.

What TMA Provides

A microboard is a non-profit organization created for the benefit of a person with a disability and composed of friends, family, and community members who assist in developing and sustaining tailored supports for that person. A microboard must

have at least five people who form a volunteer board of directors committed to working with and on behalf of the person with a disability. In many cases, microboards become providers under Medicaid waivers to provide waiver services, such as PAS.

Ruthie-Marie Beckwith, PhD, the executive director of TMA, reports that it typically takes about a year to start up a microboard, from the time of the first meeting until the microboard is legally established. This timetable is based on a group receiving extensive support, consultation, and technical assistance from TMA or a similar organization. TMA has laid out all the steps very clearly, has "boilerplate" forms, understands state policy and rules, and helps to "walk people through the process." Their Web site provides a wealth of documents and other materials, links to organizations, and links to Web sites of individual microboards. Beckwith and her staff provide extensive training, facilitate meetings, review the application to become a state-approved provider under Tennessee's Home and Community Based Waiver, and continue to provide on-going technical assistance to the microboard once it is formed. Beckwith reports that the process of setting up a microboard typically leads to increased consumer and family empowerment and clarity about what services and supports are most helpful. The microboard develops services through a person-centered planning process that is completely tailored to the needs of the individual for whom the microboard is established. The microboard provides long-term support over time, ensuring that individuals with a disability continue to receive the services they need and want.

Organizations Involved with TMA

The impetus for microboards has come mainly from family members of people with disabilities. Beckwith sees it as critical that the microboards empower consumers with disabilities themselves. People First of Tennessee, a non-profit organization that advocates for the rights of people with disabilities, has been a big supporter, and the two organizations have convened joint conferences.

TMA also partners with the College of Direct Support (CDS), which provides training for people who provide services. As part of their membership in TMA, all of the microboards are enrolled free of charge in CDS. TMA has adapted three courses from CDS (Introduction to Developmental Disabilities, Abuse Prevention/Maltreatment, and Safety at Home and in the Community) that can be used to satisfy three of six state-mandated trainings that must be completed prior to working for a person with a disability. In addition, TMA has adapted other CDS courses to satisfy other state-training requirements.

Current Funding, Costs, and Other Financial Issues (TMA)

The Tennessee Council on Developmental Disabilities has funded TMA since 2000. The original grant was for $75,000 per year, an amount that has recently been reduced to $50,000 per year, and the organization expects to be self-supporting next year. TMA generates funds through membership fees of $10 for microboards that provide natural supports and one percent of the operating budget of a microboard that provides paid supports; technical assistance fees that depend on the type of waiver; charitable donations; and fund-raisers. Since the first microboard was started in 2002, more than 30 microboards have been started across Tennessee. At

any given time, Beckwith and her staff may be working with 100 or more families in the process of starting microboards.

Initial startup costs for a microboard can range from $2,000 to $10,000, depending on how many people are providing services. Even when waivers cover the cost of the services, the initial capitalizing of the microboard can be a burden for people with disabilities and their families. TMA works with microboards to help them understand the costs involved, to figure out creative ways to generate funding, and to set up the microboard to function as smoothly as possible.

Description of Freedom Co-op Inc. and Other TN and IL Cooperatives
About three years ago, a group of individuals with disabilities in Memphis and their friends and family approached Beckwith and TMA about setting up multiple microboards that would support a number of different people with disabilities, using the same core group of people. Beckwith advised them that the time commitment would be too great for the same people to serve on multiple microboards. In subsequent discussions, Beckwith and the group evolved the idea of a "macroboard" that would serve multiple people with disabilities, and from there, they set out to establish a cooperative.

Consumers with disabilities and their families worked closely with Beckwith and TMA and the CIL in Memphis. They also consulted with Holly and Gale Bohling of Bohling Inc., whose Human Services Cooperatives (described in detail in another section) provided the model for the cooperative in Memphis. The group worked on the project for about a year and then put it on hold until they could obtain startup funding.

Very recently, the Tennessee Council on Developmental Disabilities provided a five-year establishment grant for starting cooperatives in Tennessee. The current total budget is approximately $77,000 from the Council (including a match grant). They are also seeking another development grant from the state waiver agency—the Tennessee Division of Mental Retardation—for $60,000 for startup and initial services. The current grant will enable a new consumer-run cross-disability cooperative, Freedom Co-op Inc., to open its doors in late 2007 at the Memphis CIL, which is providing free rent. The grant allows people who have mental retardation to participate in the cooperative, but Beckwith reports that they have also reached agreement with the Commission on Aging and Disability, so that people who have services under that waiver can also participate in the cooperative. Consultation from Bohling Inc. is built into the grant, allowing the cooperative to have access to that organization's wealth of knowledge and resources, which are described in more detail in another section of this report. Over the past few years, Beckwith and others have also been engaged in conversations with people with disabilities and their families in the middle and eastern parts of Tennessee, and the group plans to open two more cooperatives in those areas during the five-year grant.

Beckwith of TMA and the Bohlings of Bohling Inc. have also been working with communities in Illinois to establish cooperatives there. In August 2007, the Illinois Council on Developmental Disabilities awarded funding of approximately $550,000 for two years to develop both microboards and human service cooperatives

throughout the state of Illinois. More information is available at the project Web site, http://www.managingtheartofliving.org

Challenges, Benefits, and Recommendations

Startup funding. One of the biggest challenges for both microboards and cooperatives is startup funding. Organizations that provide services must have operating capital and it can be hard for consumers and families to raise. At the beginning, with expenses such as liability insurance and the cost of the initial payroll for people providing services, these endeavors are expensive, and that can be frightening for members. However, in Beckwith's experience, most people who are involved with microboards and cooperatives know how to be extremely frugal, and once the initial funding is in place, these organizations can be economically viable over the long run.

On the basis of her experience setting up both microboards and cooperatives, Beckwith estimates that it takes a minimum of two years to start a cooperative, from the time of the initial meeting until services are available. More time is required for a cooperative to be fully established and running smoothly.

Advise and technical assistance. Beckwith notes that finding technical assistance and outside expertise in setting up cooperatives is absolutely necessary for success. She recommends that groups get advise on how to structure the cooperative, what policies and procedures to institute, how to become a provider, how to create a viable business plan, and other business aspects. She also notes that it is important to find the right local, state, and national organizations to support the cooperative.

Microboards and PAS cooperatives in support of employment. Beckwith believes that microboards and PAS cooperatives have great potential for supporting employment. For example, in Tennessee, some microboards have become providers through the state Department of Vocational Rehabilitation (VR), allowing them to provide and bill for services, such as assessment and job placement that are specifically tailored to the needs of the person with a disability who is served by the microboard. A PAS cooperative that was focused on employment could also potentially develop a relationship with VR to provide VR-funded PAS and other supports for work. Beckwith has also worked in Tennessee and New Mexico to start microenterprises, in which people with disabilities create one-person or other small businesses and self-employment networks. Microboards, because they are personalized to work with each individual's employment issues and challenges, work well in conjunction with supported employment programs, and cooperatives centered on employment could also form partnerships with supported employment organizations. Finally, Beckwith points out that both microboards and cooperatives that were focused on employment could potentially link to Ticket to Work employment networks, another resource for organizations with an employment focus.

Finally, Beckwith notes that microboards and cooperatives only happen when people take initiative and maintain their momentum over time. As someone who has worked with microboards for many years, Beckwith sees PAS cooperatives as a brand new phenomenon that are right now "where microboards were six years ago." Cooperatives, like microboards, provide a structure that sustains people over time, giving them control over their services.

Bohling Inc. and the Federated Human Services Cooperatives (HSC)

Bohling Inc. is a consulting firm that helps to develop human service cooperatives (HSC). These cooperatives are organized by and for people who use human services like PAS, as well as their families. Local HSCs collectively own the Federated Human Service Cooperative Development and Support Center (Federated HSC) that Bohling Inc. established in 2004. The program has evolved to develop and consult to cooperatives in Arizona, California, Colorado, Illinois, Michigan, New Mexico, and Tennessee, among other states. For example, the Federated HSC consulted with BRINCS in Jackson, Michigan, which is an established cooperative that is described in a separate section of this report. The Federated HSC is also providing consultation to Freedom Coop Inc., which will soon open its doors in Memphis, Tennessee, and to a new initiative to develop both cooperatives and microboards in Illinois. (Those efforts are described in more detail in the section on Tennessee Microboards Association.) Below, we describe other human services cooperatives that Bohling Inc. and the Federated HSC have helped to start.

History and Mission

The initiative for Bohling Inc. originally came from people with disabilities and their families who wanted to find a way to create services and supports that were more responsive to their needs. Gale and Holly Bohling, who had extensive experience in human service delivery systems and public administration, created a for-profit company, Bohling Inc., to respond to those needs. In 1990, the Bohlings designed a program—Creative Networks—which provides in-home supportive services to people with disabilities and seniors. After selling that business, the Bohlings developed the concept of HSC in 2001. Under this model, groups of individuals who use support services and their families form an HSC to work together with state government programs, advocacy organizations, and service providers to ensure that the members receive effective and efficient services. The Federated HSC works to create HSC companies and to provide consultation and technical assistance to those who want to create HSC companies using the cooperative method and other service-oriented cooperatives.

Bohling Inc. laid the groundwork for the HSC initiative by joining forces with state government leaders, advocacy groups, service providers, and people who use human services. In partnership with Bohling Inc., the state of Arizona was awarded a Community-Integrated Personal Assistance Services and Supports (CPASS) grant from the CMS in October of 2003. The main effort of this $600,000 grant was to develop HSCs and to determine their effectiveness in enabling people with disabilities to direct their own care. The Bohling Web site reports that in 2005, grant funds totaled 18% of project funds, and that additional contributions included 27% nongovernmental funds and up to 55% state waiver funds designated for service delivery.

In 2004, Bohling Inc. established the foundation for a Federated HSC that networks with individual cooperatives and provides them with resources, support, quality standards, and guidelines. All of these efforts led to the establishment of a number of different cooperatives described below.

In 2004, Bohling Inc. and the Federated HSC created the Human Services Cooperative of Northern Arizona (HSCONA) in the Flagstaff region of Northern Arizona, in partnership with The Center for Habilitation. Next, the organization worked to create a second Arizona Human Services Cooperative called GALA HSC (recently renamed AZA United), which was developed to support Latino families and children with autism. The third Arizona HSC to be developed was Inspire HSC, which focuses on providing supports to young adults who are in the transition from school to work. (More details on the operation and services of HSCONA are provided below, as an example of the HSC companies.)

Bohling Inc. and the Federated HSC also developed a contract with the Golden Gate Regional Center in California in 2005 to explore the possibility of human service cooperatives as an alternative resource for individuals with developmental disabilities. They envisioned HSC companies as an alternative resource for families and people with developmental disabilities who were transitioning out of Agnew Development Center.

Bohling Inc. and the Federated HSC have also met with groups in Colorado, Illinois, Michigan, Tennessee, and other states. Some of the results of those consultations are described in separate sections on BRINCS in Michigan and the Tennessee Microboards Association, which also helped to start Freedom Coop Inc. and the Illinois cooperatives.

What Bohling Inc. and Federated HSC Provide
The Federated HSC and Bohling Inc. jointly employ a team of advisors who offer support and technical assistance to groups of people who want to start an HSC, including a wide variety of services. They help groups organize their cooperative structure, offering templates and guidance for business aspects, such as articles of incorporation, bylaws, business plans, budgets, staffing plans, technical systems, and negotiation of contracts and grants. They also offer consultation on leadership, structure, membership campaigns, and community and cooperative education, as well as help in selecting management systems for the service delivery. On-going consulting support to the cooperatives may include: access to a national network of professional resources, cooperative education and training, facilitation of management operations, assistance in quality assurance audits, and incident management, as well as facilitation of communication between HSC companies and advocacy groups, governmental agencies, professionals associations, and other cooperatives.

Other Organizations that Work with Bohling Inc. and the Federated HSC
Bohling Inc. and the Federated HSC have developed many partnerships with public and private sector organizations. One partner is ResCare, a private provider of services to people with disabilities, which bought the Creative Networks service organization originally created by the Bohlings. The Federated HSC has partnered with the Tennessee Microboards Association and other microboards on a number of projects, as well as the Center for Self-Determination, which focuses on person-centered planning. Bohling Inc. has also worked closely with a research team from the University of Colorado's Health Sciences Center, which has helped to evaluate services and member satisfaction.

Description of HSCONA
The evolution of HSCONA (the first HSC Company) and the services it provides, illustrates how HSC methods work. Human Services Cooperative of Northern Arizona (HSCONA) was started in October of 2003 and incorporated as an asset-owned cooperative in Colorado. Federated HSC companies can be asset-owned or designed as member-driven non-profits. They are often incorporated in Colorado because that state provides a good legal structure for asset-owned cooperatives. HSCONA was founded on the independent living model, encouraging self-determination and inclusion. By its third year of operation, HSCONA had 20 members, a majority of whom are young adults with cognitive or developmental disabilities.

Governance. Holly Bohling, vice president of Bohling Inc. noted that each cooperative defines its own membership rules, based on the needs of the group. Usually, members must use the services at least once per year and bring funds to the organization via membership fees or use of services that are paid for by an outside funding source. Cooperatives can require membership dues but HSCONA has waived those in favor of simply requiring a minimum participation in the cooperative in the form of bringing funds for services and accessing them.

The HSCONA Board of Directors is elected and consists of at least 80% members. The board generally appoints a mediator who is not a member to help settle any dispute, which is recommended for greater objectivity. HSCONA prohibits people from simultaneously serving on the board and working as an employee. This can sometimes be an issue, as members often serve as PAS workers for other members. Assistants may be present at board members, as needed by the members.

HSCONA has committee chairs and community partners that are essential for sustaining the cooperative. These invaluable partners have included local CPAs, attorneys and others. The cooperative has diligently engaged in succession planning and leadership training to ensure sustainability.

Funding and Costs. HSCONA has relied heavily on revenue from a contract with the state of Arizona, as well as from Medicaid dollars for PAS brought in by members. In addition, they have seen a moderate amount of private pay situations.

Services. From the beginning, HSCONA focused on providing PAS as one of its core services. Most members are not employed and, therefore, do not require workplace PAS. Instead, the PAS is generally delivered in the home or community and includes:

- Attendant Care
- Respite
- Habilitation and tutoring
- Housekeeping

There is a great deal of variation in the amount of PAS that members need and use, ranging from about 15 hours per month to 8 hours or more per day.

Beyond PAS, HSCONA and the other HSC companies envision providing additional services, including:

- Durable Medical Equipment
- Benefits Planning and Assistance Counseling
- Mental Health Peer Counseling
- Housing Assistance

PAS Workers. PAS workers may be recruited by the cooperative, as well as by individual members. Recruitment methods have included direct recruitment within the members' own networks and as newspaper postings. The HSCONA board has also been involved in recruitment. HSCONA holds a quarterly meeting for members and workers, to enable them to network, feel a sense of connection, and exchange or find PAS jobs and workers, as appropriate. HSCONA members may assist each other with screening and selecting workers, depending on the member's wishes and family availability and involvement. All workers receive the following training:

- CNA
- CPR
- First Aid

Challenges, Benefits, and Recommendations

Financing and business planning. Holly Bohling, vice president of Bohling Inc., noted that financing is a challenge for all new organizations and businesses. Although the Federated HSC is not in a position to give funding to assist with necessary startup expenses, they do work with groups that want to start HSC companies to find creative ways to find revenues. She stated that it is essential to put a lot of energy into the creation of the business plan, to look at possibilities for state contracts, and to find alternative resources when state contracts are not possible. An initial barrier to cooperative development is that people are sometimes afraid they will lose their individuality or their benefits by participating in a cooperative venture. However, Bohling reported that these fears generally lessen once people make a commitment and begin to see the benefits of joining collectively with others.

Factors that promote cooperative success. Bohling Inc. and Federated HSC offer access to startup templates and other documents that can reduce development time. Bohling noted, however, that HSC companies, like all organizations, take time and commitment to develop. A committed group of people is probably the most important component of success. Beyond that, Bohling enumerated three main factors that determine whether or not a cooperative will flourish:

- Are the services that people want amenable to a cooperative structure?
- Can services be funded?
- Does the cooperative have enough technical support and expertise?

Cash flow and insurance issues. Cash flow, once the cooperative is started, can be a barrier, especially when state programs sometimes delay payments. In addition, it may be tricky to find good liability insurance, as insurance companies are not often familiar with the cooperative model of providing services. Bohling Inc. has found

an insurance broker who is familiar with the cooperative model and partners to assist HSC companies in finding a good policy.

Other benefits to people with disabilities. According to Bohling, cooperatives offer the advantage of spending less money on administration and more money on direct service provision, which benefits both users of services and workers. HSC companies often hire people with disabilities to provide services to other people with disabilities, providing mutual benefit.

Bohling stated that cooperatives provide an ideal structure for providing PAS, which can increase the opportunity for self-direction and empowerment of people with disabilities. "Co-ops put those who use services in the driver's seat of their collective needs. By forming co-ops, they are in a position to democratically select their direct service professionals and benefit from each other's resources and knowledge." Although the use of workplace PAS is rare in the HSCs and the other cooperatives we examined, the cooperative model has the potential to be further developed to support employment.

Bridge to Recovery Independent Network South (BRINCS)

Bridge to Recovery Independent Network South (BRINCS) is a consumer-owned cooperative whose membership has mental illness and/or developmental disabilities. The cooperative was first started in 2000, but has recently restructured its board to give more control to consumers.

History and Mission
In 2000, a group of people in Jackson, Michigan, developed the idea for a cooperative that would be owned and run by people with mental health disabilities. They started the Michigan Consumer Cooperative (MCC). This cooperative was included in a grant application for federal funding from the Real Choice Systems Change grant (described below under Funding). In 2005, the cooperative was renamed Bridge to Recovery Independent Network South (BRINCS). BRINCS described its mission as follows:

> To provide members the opportunity to pool their resources, power and collective voice; to maximize the amount and quality of benefits and supports they select.

In 2006, BRINCS sought consultation with the Federated HSC (described in more detail in the section on Bohling Inc. in this report). Working with Federated HSC, BRINCS was able to develop its board structure and bylaws so that consumers had more control, and to negotiate new relationships with Medicaid funding sources, which have helped the cooperative to become more solidly established.

Structure and Governance
When the board of directors was first developed for MCC (the prior name for BRINCS), the board included mental health consumers, family advocacy representatives, and local and state mental health system representatives. BRINCS has recently established a new structure for the board of directors, which is elected by the members of the cooperative. All of the board members are consumers with mental health or developmental disabilities. An advisory panel of community professionals advises within the various areas of the members' professional expertise, such as accounting. The people on the advisory committee do not have to be individuals with disabilities. According to a BRINCS member, a recent independent evaluation of BRINCS praised this change in governance, noting that control of the cooperative is now in the hands of consumers rather than professionals.

Organizations Involved in Starting and Maintaining BRINCS
Over the years, BRINCS has received support from many state and national advocacy organizations. These include, among others, the ARC of Michigan, Justice in Mental Health, the National Alliance for the Mentally Ill (NAMI), the Michigan Disability Rights Coalition, and the Association of Children's Mental Health Local Community Mental Health Service Programs (CMHSP). On the local level, BRINCS was supported by local CMHSPs, especially LifeWays and several Department of Community Health (DCH) representatives. BRINCS members report that they are

currently working with three local support groups started by Schizophrenia Anonymous, NAMI, and Mind Changers.

Current Funding, Costs, and Other Financial Issues
From 2001-2004, BRINCS received funding from the Real Choice Systems Change grant number 18-P-91663/05. This grant was awarded to the Michigan Department of Community Health by the Center for Medicare and Medicaid Services (CMS). BRINCS was one of the recipients of the funding, which was intended to improve community long-term support systems to enable adults and children with disabilities to live and participate in their communities. The Michigan Association of Community Mental Health Boards was another funding partner in the project (Center for Medicare and Medicaid Services, 2004; Michigan Department of Community Health, n.d.).

Projects in Kalamazoo and other Michigan communities also received funding from the Real Choice Systems Change grant, and they are currently working with Bohling Inc. and the Federated HSC to incorporate as HSC companies.

BRINCS currently receives funding from Medicaid and LifeWays. LifeWays is an organization that manages the behavioral health treatment and services for Jackson County residents. BRINCS uses the services of a person who acts as a fiscal intermediary and keeps track of each member's budget.

Consumers
All of the people who receive services from BRINCS have mental health and/or developmental disabilities. It is not required that they be involved with the mental health system to receive BRINCS services, but they must have a diagnosis of mental illness or a developmental disability. Currently, 18 people receive services, including 9 men and 9 women. All are between the ages of 30 and 60 years.

What the Cooperative Provides
The main service is peer mentoring and individuals provide many different forms of assistance. Members work with each other on transportation, advocacy, getting out into the community, crisis management, and coordination of outside services. Some of the members have funding for Community Living Support (CLS), such as assistance with chores and housekeeping, and other members of BRINCS provide those services. To this end, the owner-members of BRINCS sometimes work as PAS workers, as well as receiving services as consumers.

PAS in support of employment. When BRINCS was first started, in 2000, the organization did not focus on employment issues. BRINCS' original goal was to assist people who were transitioning from institutions to community life, to help them live independently and find appropriate support services. More recently, however, members have received VR services and on-the-job training opportunities. Currently, 7 of 18 people are working at jobs that include assisting in the school district office, stocking shelves at a local grocery store, and other retail employment. In addition, one of the BRINCS' members planted a micro-enterprise garden on the cooperative's grounds and has begun selling fruits and vegetables at a roadside stand.

Training. Self-determination training is offered to all members. Members learn how to choose the supports and services that best meet their needs, and they learn how to advocate for themselves in the mental health system. In addition, one of the members is the process of obtaining peer support specialist training. After she is certified, she could be a resource for other members to receive peer training from her.

Challenges, Benefits, and Recommendations

Importance of technical assistance. Even after receiving funding from the Real Choice Systems Change grant, BRINCS struggled for a number of years to establish and maintain services as a non-profit. At the time, they were working with service providers who opposed the idea of BRINCS collectively bargaining to get better services. A few years ago, BRINCS sought assistance from Bohling Inc. and the Federated HSC. This technical assistance has been extremely helpful in getting BRINCS established as a functioning cooperative, with a consumer-controlled board of directors.

A flyer developed by BRINCS explains that it recently incorporated as a cooperative with a consumer-controlled board for the purpose of providing greater benefits to the members by:

- Increasing individual accountability
- Enhancing a member's quality of life, by providing important needed services
- Offering broader choice and greater control
- Tailoring benefits to consumer's needs, rather than trying to fit into an existing system
- Offering more choice with Person-Centered Planning
- Increasing purchasing power
- Providing a stronger collective voice
- Enabling a greater percentage of dollars spent directly on supports and services
- Providing mutual support among members and families
- Providing access to real-time information and training

Services tailored to individual needs. Although the change to a consumer-controlled board of directors is fairly recent, BRINCS members believes that the cooperative has empowered consumers, by offering broader choices and greater control over supports and services. They believe that services are more tailored to individual needs, when they are provided through the cooperative. Consumers profit from having skills training in how to serve on a board and make collective decisions.

Expertise in cooperative structure and business. BRINCS staff recommend that people who seek to establish consumer-run cooperatives find experts in cooperative structure, board development, and the business side of human services, so that they can set up the right kinds of structures from the beginning. Technical assistance and expertise can help a cooperative get off the ground and provide excellent services to people with mental health and developmental disabilities.

Stockholm Cooperative for Independent Living (STIL)

Stockholm Cooperative for Independent Living (STIL) is a consumer-directed cooperative that was founded by and for people with disabilities in Stockholm, Sweden. Only people who use PAS may become members with voting rights in the cooperative and serve on STIL's board. STIL acts as the employer of record for the PAs, who work directly for the PAS users. Funding for PAS comes from the national Social Insurance fund, and is based on the need for PAS rather than means-tested. For more than twenty years, STIL has served as a model to service cooperatives all over the world.

History and Mission
In 1984, a group of people with disabilities in Sweden created STIL. Inspired by presentations on the U.S. independent living movement by Ed Roberts and Judy Heumann at the first Scandinavian Conference on Independent Living, the Swedish consumers established STIL as a cooperative to take control of their PAS. The mission of STIL has remained constant over more than twenty years:

> STIL's aim is to empower members by providing the practical means for self-determination, independence and integrity in their daily lives. This includes providing role models, sharing experiences, insights and mutual support.

STIL was instrumental in reforming the law that regulates the provision of services to about 13,000 people in Sweden who have the most need for PAS services. According to the reformed law that was established in 1994 through the efforts of STIL and other organizations, the PAS services provided by the Social Insurance fund must provide a "good quality of life," and there are no limitations on how eligible people use the services. For example, people who receive Social Insurance funding for their PAS can continue to receive those services while traveling in the European Union for up to 12 months and elsewhere for up to 6 months, and students are eligible for full PAS for as many years as they are studying abroad. The services are completely flexible and based on the individual needs of the users.

In contrast, people who need less than 20 hours per week of PAS are not covered by Social Insurance, but rather by the local governments. These in-home supportive services are provided to the level of a "reasonable quality of life," generally at home, and there is much less flexibility. STIL is not involved in the provision of these services, only the Social Insurance-funded services.

Structure and Governance
STIL is a member-run cooperative, with a board of directors. All members have extensive need for PAS services and only members serve on the board. People pay the equivalent of about $50 to join and about $15 per year for continuing membership. Prospective members must pass a course in directing their own services and then be voted in by the membership. The STIL cooperative is managed by and for people with disabilities who use PAS services. Adolf Ratzka, a founding member of STIL, believes strongly that workers should not be involved as members of the cooperative, as this would dilute the consumer-directed focus.

Organizations Involved in Starting and Maintaining STIL
The cooperative movement is highly popular in Europe; there are many credit unions, housing societies, condominium associations, and farmers' cooperatives. STIL received help and free advice from the cooperative development association in Sweden, including assistance in drawing up the first contracts with local governments and other legal issues. The cooperative development association also benefited, as it could use STIL as an example of a social cooperative that worked.

Although STIL is different from an independent living center, the organization shares many of the same ideals and goals. In Sweden, PAS cooperatives and IL centers have always been mutually supportive, and many of the Swedish cooperatives include "IL" for independent living in their names.

Current Funding, Costs, and Other Financial Issues
Funding for STIL comes from the national Social Insurance fund, which is not means-tested, but rather based on assessed need for PAS. Each member's PAS needs are assessed and the need is expressed in terms of number of hours of services per week. Each member receives an amount that covers that cost, and the funds are transferred from the national Social Insurance fund to the individual's account at STIL.

The current rate is of funding from the government is 229 Swedish krona (SEK) or about $35 U.S. dollars (USD) per hour. Slightly less than 7% of this amount (15 SEK or about $2.30 USD per hour) goes to the cooperative for administration. With these reimbursements, STIL is able to operate as a self-sustaining business with an annual budget equal to more than $25 million USD.

STIL provided information about the overall cost of PAS in Sweden (not just at STIL). The 13,000 people who are eligible for services funded by the national Social Insurance receive an average of 104 hours per week, at a cost per hour of service of 229 SEK. Thus, the average annual cost per person is 1,238,432 SEK, which is equivalent to about $190,000 USD per person per year. However, it is important to note that the 13,000 people who receive Social Insurance funding for their PAS represent only a fraction of a percent (0.14 %) of the Swedish population of about 9 million. They are people with the highest need for PAS, and Sweden has almost no people living in institutions.

Consumers
STIL is a consumer-directed cooperative that was founded by and for people with disabilities. It currently has 240 members, all of whom are eligible for PAS services from Sweden's national Social Insurance fund, described above. Adolf Ratzka, a founding member and PAS user, estimates that there have been about 500-600 people who have received STIL services over the life of the cooperative. STIL has also been a role model for cooperatives throughout Sweden and internationally, so that it has indirectly benefited many more people over the years.

The vast majority of STIL consumers have significant physical disabilities. There have been some blind people and some with intellectual and learning disabilities.

However, most people in Stockholm with significant intellectual disabilities are served by another cooperative called JAG. JAG specializes in serving people with multiple disabilities, many of whom use "deputy bosses" to direct their care (Tengstrom, n.d). For that reason, STIL tends to refer people who need those services to JAG. STIL has very few consumers with mental health disabilities, and only as a condition secondary to a physical disability. (People with mental health disabilities are not eligible for PAS in Sweden, unless they also have a physical disability that necessitates PAS.)

The majority of PAS users at STIL are women. Once they join the cooperative, people tend to stay in it over time, and the STIL population is aging, with the median age currently estimated at over 60 years. Only rarely have children under 18 years been members of STIL.

What the Cooperative Provides

The number of hours of service that a consumer is allotted is based on the disability and the need for PAS. Currently, the 13,000 recipients of Social Insurance receive an average of 104 hours of PAS per week. This average includes a small number of people who need 48 hours of assistance per day, because they need two workers around the clock. STIL's average hours per week may be slightly lower than the national average, because people with multiple disabilities who are unable to direct their own care would be more likely served by JAG.

As an adjunct to providing PAS services, STIL has contracted with specialized legal experts who will represent individual members in legal disputes with government funding agencies. A member who uses this service pays a fee of 500 SEK (less than $80 USD) per case, with no additional costs. Any remaining costs of the legal services are handled by the cooperative.

PAS in support of employment. For a long time, STIL emphasized hiring people with disabilities (including cooperative members) to fill administrative positions in the organization. This policy has had the advantage of providing training and job opportunities for people with disabilities, and some former employees with disabilities have found other jobs after they gained experience and skills at STIL. In recent years, STIL has hired some non-disabled individuals to fill administrative positions, although the majority are still filled by people with disabilities. Ratzka noted that this new approach has the advantage of allowing the organization to fill some positions more quickly and allowing people with disabilities to focus more on the advocacy work. STIL always makes certain that people with disabilities represent the organization in public and in negotiations with the government and others.

At the present time, only a small percentage of the STIL members are working (less than five percent). This is due, in part, to the aging population of the cooperative, where the median age is over 60 years. Some younger STIL members do use PAS at work. For example, one man in his thirties works at universities all over the country. He commutes by plane and has hired PAs in all the different places that he usually travels. Using the funds they are allotted, STIL members are free to hire as many PAs as they need to provide the services, wherever they are needed.

When a PA accompanies a member to work, the PA typically assists with work-related tasks, such as finding files or handling books or other materials, and personal care tasks, such as eating or using the restroom in the workplace. PAs frequently assist with transportation. The individual members can choose any kind of services they need; there is no list of approved services.

Who provides services? Currently, about 1,200 workers provide services to the PAS users in STIL. Almost all are between the ages of 18 and 64 years, and about 60% are women. It is not known whether any of the PAs have disabilities. Generally, family members do not provide services. Before 1994, when the services were reformed, there was insufficient assistance, and many people used unpaid family members. Since the reform, some family members have continued as paid assistants. STIL does not encourage this, but leaves it up to consumers. The main requirement to be a PA is the ability to do the job and to take direction from the consumer.

Wages and benefits. PA's wages are based on rates that are bargained by the unions that represent them; they are higher than pay rates in the United States (as are most other wages in Sweden). Ratzka notes that PAs' wages are better than those of people who drive taxis or clean for a living, and he says that unions are working to upgrade the professional standing of the PAS workers. PAs receive health benefits through social insurance.

Training. All consumer employers at STIL receive training in how to be a "boss"; completing training classes is a prerequisite for becoming a member of the cooperative and employing one's own PAs. The courses cover topics such as assessing personal needs, negotiating with government agencies for funds, advertising for assistants, interviewing job applicants, and setting up a job contract. Other important topics include scheduling, training, supervising, and—if necessary—firing assistants. Other members of the cooperative, who have extensive personal experience employing assistants, teach the classes. Consumers also participate in periodic peer support sessions led by experienced PAS users, and they can call on peer support staff at the office whenever they need assistance in managing their PAS. Consumers train their own PAs to provide the exact services they need and in the manner they prefer them to be administered.

Arranging for services: Rights and responsibilities. STIL acts as the employer of record for the PAs, but each member is completely in charge of the individual services. Members recruit, train, schedule, and supervise their own PAs. The members are responsible for finding the assistants. There is no pool of assistants from which to choose, although STIL does have an assistant pool for emergencies. Two users may decide to share the services of the same PA, but that arrangement is up to the users.

Transferability

The STIL model has been replicated all over Europe. In Sweden alone, there are more than a few dozen cooperatives, many of which are modeled on STIL. STIL has helped PAS users to start their own cooperatives, patterned after the STIL example, in Germany, Norway, Belgium, and the Czech Republic, among others. STIL has also organized international workshops and seminars, as part of its membership in ENIL, the European Network on Independent Living. Over the years, STIL has

trained more than 1,000 people on the cooperative model and how to manage PAS services. One of the most important requisites for transferring the STIL model is the availability of sufficient national funding for PAS. In Sweden and many other European countries, there is a good fund base for funding cooperatives.

Challenges, Benefits, and Recommendations

Challenges. STIL faces a number of current challenges. Ratzka noted that the average age of people in the cooperative is increasing and there is not a large influx of younger people. Some young people feel that the cooperative requires too much time and energy commitment to provide the peer support. He stated that it is important to find ways to do better outreach to young people. In addition, private enterprises are increasingly competing with cooperatives for the business of administering PAS services. In 1994, about 15% of the people who were eligible for services in Sweden chose cooperatives. In 2004, it was down to 12%. Some of the companies that have been competing for the market share have used very aggressive marketing, and some may have offered illegal payments to enroll consumers with disabilities in their programs. The Social Insurance system is now investigating, which may result in increased controls that will effect all organizations that deliver services, including those that have not engaged in illegal tactics.

Membership control. The greatest benefit of STIL is that the consumers who use PAS services are the members who control the organization. Members report that this has made a big difference in their quality of life. STIL emphasizes self-determination and empowerment in every aspect of life for consumers. Cooperative members represent STIL in every aspect of public life.

Benefits for workers. STIL is completely consumer-directed and works for the benefit of PAS users. Nevertheless, there have also been benefits for the PAS workers. Ratzka reported that the workers have a better quality of life in the cooperative than in semi-institutional settings. They are able to work on a one-on-one basis, and to negotiate the responsibilities with one person instead of with a bureaucracy. Ratzka noted that the unions were at first opposed to the cooperative, citing concerns that the cooperative would take rights and benefits away from the workers. Now, the unions have come around to the idea that the cooperative is beneficial to workers as well as consumers with disabilities.

Creation of jobs. Even more broadly and in Sweden as a whole, well-funded PAS services have had a large economic impact in terms of creating jobs. Across the country, the 13,000 people who qualify for Social Insurance funded PAS employ more than 45,000 people. Nationwide, this workforce is similar in size to the largest employer in Stockholm, which employs about 50,000 people.

Social policy and sufficient funding. Ratzka reported that the cooperative model has worked well in Sweden, because the social policy structure and laws have granted cash benefits that are based on the consumers' need for services and the amount needed to sustain a good standard of living for PAS users. It would not work well in countries where there are few cash benefits for PAS. STIL had the advantage of working with the government to set up the services and negotiate payment rates at the time the laws were first being reformed. STIL was able to negotiate agreements,

to ensure that the payments covered decent wages and social insurance for the workers, as well as cooperative administration and personal administration for the consumer (such as phone calls and computer expenses necessary to manage the services). They successfully made the case to the government that consumers must be able to choose the PAS services they need, hire as many workers as they need, and use them wherever they are needed, including workplace PAS, transportation, and travel inside and outside the country. In turn, the cooperative has built-in efficiency, because the consumer handles all the middle management tasks.

Main advantages of cooperatives. It is interesting to note that STIL was at first viewed by some political parties in Sweden as "too individualistic" and too much based on the U.S. independent living model. Setting up the organization as a cooperative helped to make it more palatable to a wide range of people of many political orientations. In fact, Ratzka says that establishing the organization as a cooperative was a "political necessity" in Sweden in the 1980's. He states, "Always keep in mind that the cooperative is not the end in itself. The main advantages of the cooperative structure are the democratic system, the training emphasis, and the mutual support. In another political climate you might want to call it a 'share-holding company' or a 'membership association.' The core value is to keep the control in the hands of the members who use the service."

ULOBA Cooperative on Personal Assistance, Norway

ULOBA Cooperative on Personal Assistance, located in Drammen, is the only PAS cooperative in Norway. It is available to anyone who has a need for PAS, and currently serves more than 700 people nationwide. ULOBA is owned by people with disabilities and operated as a non-profit cooperative that serves as the employer of record of the PAs. ULOBA emphasizes peer training of the owners, who then recruit, train, schedule, and supervise their own PAs.

History and Mission
ULOBA was started by people with disabilities in 1991. It is owned and run by people with disabilities according to the philosophy and principles of independent living. Originally, five people with disabilities started ULOBA, because they were tired of being controlled by their municipality, which hired and sent workers to provide PAS. They wanted to make their own decisions about services and choose their own workers. They looked at models that people had used in other countries, such as STIL in Sweden, and set up the first PAS cooperative in Norway. It took about three years to get a contract with the municipality. Since then, ULOBA has negotiated contracts with about one-third of the municipalities in Norway. ULOBA continues to outreach to other people with disabilities and is open to negotiating contracts and providing services anywhere in the country.

Structure and Governance
ULOBA has two levels of membership: subscriber and owner. Initially, people with disabilities pay a subscription fee of about $80 and take the course to learn leadership skills and how to manage their PAS. After individuals have completed the course and hired their first PA, they are eligible to become an owner, which costs about $170. There are no other ongoing fees, and the ownership fee is refunded if they leave the cooperative. ULOBA is run by a board of directors that is elected by the owners, based on one vote per owner. The board chair and vice chair must be PAS users and ULOBA seeks to maximize participation of people with disabilities on the board. The current board consists of six people with disabilities and one non-disabled person. PAS workers are not permitted to sit on the board.

Organizations Involved in Starting and Maintaining ULOBA
A variety of different disability organizations were helpful in starting ULOBA. One ULOBA consumer reported that unions are generally not supportive of the cooperative.

Current Funding, Costs, and Other Financial Issues
In Norway, all funding for PAS services comes through the municipalities, and funding for work assistants comes through the federal government. ULOBA has negotiated contracts with 140 of 434 municipalities and with the federal government to provide services for ULOBA owners. ULOBA administers the funding and bills the municipalities and federal government for the hours of service used by its owners. In the past year, ULOBA billed the municipalities approximately 435

million Norwegian krone (NOK) or about $80 million USD for PAS, and the federal government approximately 4.6 million NOK (about $840,000 USD) for work assistance.

Consumers
ULOBA provides services to more than 700 people across Norway. ULOBA's owners have control over the assistance, including who is hired, which tasks they perform, where, and at what times. The large majority of ULOBA owners are between the ages of 18 and 64 years, and there are more women than men. An ULOBA owner reports that consumers have a variety of different disabilities, but that, in Norway, it is generally much easier to get PAS for physical or intellectual disabilities than for mental health disabilities.

What the Cooperative Provides
ULOBA owners receive a wide variety of services, including assistance with transportation, communication, cooking, eating, reading, and home chores. They may also receive assistance with shopping or attending events in the community. People receive services based on their disability and the number of hours they need. The average number of hours per week is 42.2. Generally, each member has a single assistant, although they may share workers if they choose.

PAS in support of employment. When ULOBA was started, work was not an initial goal of the cooperative. People were focused first on getting their basic needs met. An ULOBA member noted that many people with disabilities had to feel empowered to take control of their basic PAS services, and only later began to think that work was possible.

Currently, in Norway, there are different systems for providing personal assistance versus work assistance (WA). The municipalities pay for PAS, which is primarily provided at home or in the community, and the federal government pays for work assistance. An ULOBA consumer explained that it is harder to get WA than PAS, but that ULOBA and other disability groups are fighting to make workplace assistance more readily available.

To date, ULOBA is the provider for 30 worker assistants (WAs) who assist 30 consumers at work. A WA can help with work-related tasks, such as handling paperwork, answering phones, or performing other clerical work, as well as with personal care, such as assistance with eating or using the restroom at the workplace.

Apart from the 30 ULOBA owners who are currently receiving workplace assistance, people in the organization were not sure how many ULOBA members are currently working, but they noted that fewer than 20% of people with disabilities in Norway are working. Those who do work are most frequently working in disability organizations. Like other PAS cooperatives, ULOBA provides an opportunity for PAS users to gain job experience working in the cooperative in administrative and advocacy positions. The majority of employees in ULOBA's administration are people with disabilities who use PAS.

Who provides services? ULOBA employs more than 3,000 PAs. They come from a variety of backgrounds, including health care, hospitality, retail, and even some former plumbers and carpenters. Almost all are between the ages of 18 and 64 years, and most are between 20 and 40 years. More women than men are PAs. ULOBA does not ask workers whether they have disabilities, and they estimate that few, if any, have disabilities. ULOBA does not encourage consumers to hire family members or friends, pointing out that it is often hard to take control of services when family members, especially parents, are performing them. However, it is ultimately up to the consumer to decide who delivers the needed services.

Wages and benefits. The wages and benefits of the PAS workers are determined by the municipality, rather than by the cooperative. PAs earn a base rate of 132.40 NOK per hour (slightly more than $24 USD) and also receive increased pay during nights, weekends and 15 national holidays. These wages are generally higher than people working in retail stores, especially with the differential pay for nights, weekends and holidays. Workers also receive health care benefits. Most PAs work part-time.

Training and arranging for services. The training model is similar to that of STIL in Sweden. ULOBA focuses on providing the owners with leadership skills through peer training and peer counseling. Initially, all consumer employers must take a 16-hour course, and they take another 8-hour course after one year of participation in ULOBA. Peer counselors are available to assist ULOBA members with ongoing development of their skills in managing their services.

ULOBA does not provide training to workers. ULOBA's philosophy is based on the idea that consumers know what services they need and they are the best person to train the worker.

ULOBA's consumer-owners recruit, train, schedule, and supervise their own assistants. One member noted that ULOBA as a cooperative must make the decision to fire assistants, based on the member's wishes, and that it can be difficult to fire assistants, whose rights are supported by the law.

Challenges, Benefits, and Recommendations

Changing attitudes and perceptions. The main challenge for the cooperative has been to convey the independent living philosophy to the municipalities and others in the community. ULOBA works politically with other disability organizations to secure the rights of people with disabilities. They emphasize that they are not people who need "special care," but, rather, ordinary citizens who have all the aspirations and dreams of other people. Changing attitudes and perceptions towards people with disabilities is an ongoing focus of ULOBA. For that reason, all of the people who represent ULOBA publicly are PAS users.

Peer training and support. According to the owners of ULOBA, the major benefit of the cooperative is that the people who use PAS services gain control over those services. They note that the municipalities in Norway have had a monopoly on PAS, and those services are often inflexible and paternalistic. Rather than relying on the municipalities to provide workers, the owners of ULOBA choose their own workers and direct their own services. One ULOBA owner pointed out that some people

with disabilities have been taught by the health care system and/or their families to be dependent on others to make decisions. Sometimes, this makes it difficult for them to manage their PAs. But peer training and support usually helps them become more empowered, confident, and skilled. ULOBA uses the model of training the consumers to direct their own services, and then the consumers provide training to the workers, letting them know exactly what kinds of services they need.

Commitment to empowerment. In terms of recommendations to other people who want to set up PAS cooperatives, the ULOBA owners note that the commitment to empowering people with disabilities is the most important obligation. Every country is unique, and different political and social structures may require different approaches for funding the services. But making sure that the people with disabilities are in charge of the organization and the PAS services is the core value of ULOBA.

Lessons Learned from Other PAS Cooperatives

Lessons Learned from Other Consumer Cooperatives

In addition to talking with people at existing consumer-run PAS cooperatives, we conversed with those who knew about consumer PAS cooperatives that either never started or went out of business. The experiences of these cooperatives and the barriers they encountered may be helpful to people who would like to start new consumer PAS cooperatives.

California PAS Consumer Co-op Project
The Robert Wood Johnson Foundation Independent Choices Program provided funding to start PAS cooperatives in California during the period 1997-2000. Information about this initiative is summarized in a report, "The many faces of consumer-direction: Consumer co-ops for people with disabilities who use personal assistance services" (Wheeler, Luce & Coontz, 2001). Although it had been expected that consumer cooperatives would be an effective model to promote consumer direction among recipients of In Home Supportive Services (IHSS) in California, none of the project's four attempted cooperatives was successfully established during the three years of the grant. The subtitle of the report is, "Lessons learned from a failed project: A post-mortem analysis of the California PAS Consumer Co-op project," and the report provides excellent information about the barriers that prevented the California cooperatives from being established.

At the time of the California PAS Consumer Co-op Project, more than 92% of people in California who used IHSS received those services under the Independent Provider (IP) mode. Although this was preferred by consumers and gave them autonomy to recruit, hire, train, and supervise their workers, the IP mode, at that time, provided no registry or backup and no assistance to the consumer in managing the PAS; in addition, there were unaddressed liability issues. In response to those issues, California developed the Public Authority model to assist people using the IP mode to manage their employees and other services. The Public Authority serves as the employer of record related to collective bargaining and liability issues. A board consisting of at least 50% users of PAS advises each Public Authority.

The California PAS Consumer Co-op Project attempted to establish cooperatives, to provide intermediary supports for consumers who were using IP mode, at about the same time that the Public Authority model was gaining hold in California. The cooperatives were intended to give more control to consumers than the Public Authority gave them. The project proposed to develop IHSS Consumer Cooperatives in four California counties, two in Northern California, and two in Southern California. After three years of working to initiate the cooperatives, the project was not successful in establishing any cooperatives. One cooperative in San Diego was a "near success," coming close to obtaining a 3-year multi-million dollar contract with the county. However, after delays in waiver funding that would have established a demonstration project, San Diego decided to adopt the Public Authority instead of the cooperative.

A number of factors contributed to the failure of the project, according to the analysis. Many IHSS recipients did not want to join a cooperative, because they worried that they would lose what little they had, such as their individual workers or their current service hours. (Initial consumer fears about losing workers or benefits came up as a common theme in our discussions with successful cooperatives; in some cases, the small intimate nature of the cooperative helped to allay fears.) The failure of cooperatives to take hold may also have been a question of timing, in that the disability community in California was quite involved with the establishment of the Public Authority, and had less time or energy to devote to the alternative model of the cooperative. In fact, the cooperative model, especially on such a large scale, may have required too much consumer time and resources, compared to the Public Authority, which promised consumers a say in how their services were delivered without asking them to devote as much time and energy.

On a broader level, there were questions about whether counties could legally contract with the IHSS Consumer Co-op to administer services for members. In addition, labor unions generally supported the Public Authority and opposed the idea of cooperatives, which were new and unfamiliar. In particular, the Service Employees International Union (SEIU) had organized home health workers and negotiated contracts with Public Authorities. If cooperatives had been able to establish themselves and gain contracts for services, they could have also entered into negotiations with labor unions. But labor unions had already established agreements with Public Authorities.

The attempt at establishing consumer-directed cooperatives in California, as described by Wheeler and her colleagues, also suggests that three years is too short a time to establish a cooperative. This finding is corroborated by observations of people we interviewed, who suggested that cooperatives may require five or more years of startup funding to become self-sufficient.

Finally, Wheeler and her colleagues found that, in general, organizations that promote cooperatives have little experience with disability cooperatives and that expertise in both areas is needed. For example, the California PAS Consumer Co-op Project found that the Center for Cooperatives at UC Davis had broad expertise in how to establish and promote cooperatives, but no experience with disability or other human services cooperatives. In order to promote PAS cooperatives, it is important to bring together expertise in both disability and the cooperative models and systems.

The evaluators of the California PAS Consumer Co-op Project conclude that PAS cooperatives have great promise for building social capital and a sense of community among people with disabilities. They recommend that people with disabilities who want to start PAS cooperatives consult closely with experts on cooperative structure and obtain on-going technical assistance. It may be advisable to "start small" and develop sustainable local cooperatives.

One State-level Attempt to Create a Consumer PAS Cooperative
In the late 1990s, one state provided funding for a PAS cooperative to allow self-directed consumers to manage their own services. The state director of disability services provided seed money of $50,000 to start up the cooperative. The state director thought the cooperative would help to reduce overhead and would be a good program for people who were unhappy with the agency model of services. It was a state-funded program with no Medicaid money, so the project had a lot of flexibility to develop the program.

The state director reported that, unfortunately, the effort "completely bombed." He stated that people who organized the effort were well intentioned, but did not fully understand the level of commitment and responsibility required. The project funded some consumers to receive PAS, but people in leadership roles did not follow through and, suddenly, all the money had been spent and the project could not meet payroll. The state director reported being very disappointed by the outcome. He still believes conceptually and philosophically in the potential promise of PAS cooperatives and thought that the right group of people could create the infrastructure and organization to build a successful effort. He underlined the importance of groups that want to start PAS cooperatives obtaining sufficient guidance and technical assistance, and developing a strong, detailed business plan with strategies to handle unanticipated obstacles.

Lessons Learned from Worker-Owned PAS Cooperatives

Worker-owned PAS cooperatives are a well-established model in the United States. ODEP requested that this report focus on PAS cooperatives primarily for the benefit of people with disabilities. Nevertheless, a few of the learned lessons of worker cooperatives may be helpful to those who want to start consumer cooperatives. Here, we briefly describe some of the models of worker-run cooperatives and discuss issues and strategies that may have bearing on cooperatives for the benefit of consumers.

Description of Types of Worker Cooperatives

In the United States, PAS cooperatives owned and managed by PAS workers were first established in the 1980s. The first worker-owned cooperative, Cooperative Home Care Associates (CHCA) started in South Bronx, New York, in 1985, and many other cooperatives have modeled themselves after it. Worker cooperatives have been supported and publicized by an affiliated non-profit organization—the Paraprofessional Healthcare Institute (PHI)—that works to improve the lives of workers who provide long-term care and the people who use that care. According to Whitaker, Schneider, and Bau (2005), three main kinds of worker cooperatives currently exist: the job training model, the organizing or independent caregiver cooperative model, and the cooperative conversion model.

Job training model. The main purpose of job training cooperatives is to help low-income people enter the workforce as home health aides, by providing job training and improving job quality for those workers. The organizational structure of such cooperatives is designed to provide job training in the provision of PAS services, to enhance job retention, and to promote leadership skills among low-income people. The workers are primarily women who previously received public assistance. CHCA, the first and largest worker cooperative in the United States, operates under the job-training model and employs more than 1,000 providers of home health services. (For a detailed case study of CHCA, see Inserra, Conway, & Rodat, 2002). Many other worker cooperatives have been modeled after CHCA, with the most successful example being Home Care Associates (HCA) in Philadelphia, PA. One of the key challenges of this model is that high quality training cannot be sustained by the usual wages of home care workers, so that the model requires outside funding, such as private foundation and workforce development money, to make the training and the cooperative successful.

The "organizing" model of the independent caregiver cooperative. This model focuses on organizing people who are already working as independent caregivers into a self-governing cooperative. The first cooperative organized using this model was Cooperative Care in Wautoma, in rural Wisconsin. Before the formation of the cooperative, the workers were employed as independent caregivers by individual consumers who received publicly funded PAS services. The county supported the formation of the cooperative partly as a proactive approach to dealing with fears about liability issues triggered when an individual independent worker was injured

on the job and initiated legal action against the county (S. Schneider, personal communication, November 28, 2006). The cooperative entered into an 18-month, $850,000 contract with the county, which allowed the PAS providers to continue to provide services to the same consumers. After their employment by Cooperative Care, worker-owners received a significant increase in pay and a comprehensive benefits packages, including: paid vacations and holidays, travel reimbursements, and health insurance. (For more information on this worker cooperative, see Bau & Harrington, 2003; Whitaker, 2002; and Waushara County Department of Human Services, 2003).

Cooperative conversion model. The third model for worker cooperatives is utilized when existing businesses or non-profits transform their organizational structures into cooperatives. A handful of for-profit and non-profit organizations are in different stages of converting their businesses to worker cooperatives. Known examples include Quality Care Partners, in Manchester, NH; Care at Home, in Brooklyn, NY; the Andersson Caregiving Group, in Mendocino County, CA; I Am Unique Case Management, in Raleigh, NC; and Manos Home Care, in Oakland, CA. (For more information on this type of cooperative, see Kahn, 2000, which presents an in-depth case study of Quality Care Partners.)

Issues and Strategies Related to Worker Cooperatives that May Provide Lessons for Consumer Cooperatives

Better jobs for workers may lead to better quality services. The worker-owned cooperatives and PHI have focused on workforce development of PAS workers. The major goals of all of the worker cooperatives have been to provide good jobs (including full-time work with higher wages and benefits), to improve workers' training and skills, and to empower workers as owners of the cooperatives. However, the worker cooperatives also emphasize the idea that workers with high quality jobs provide high quality services. PHI's mission is "to ensure caring, stable relationships between consumers and workers, so that both may live with dignity, respect, and independence" (Paraprofessional Healthcare Institute, 2007). PHI and multi-stakeholder coalitions, with representation by consumers, providers, and labor organizations, have pushed for "Better Jobs, Better Care" to benefit both consumers and workers (Kahn, 2003).

As one example of this approach, CHCA trains workers to support consumers as the primary managers of their own care. This worker cooperative has received numerous awards for social responsibility in business and best practices in human services (Bowman, 2001). Evaluations of worker cooperatives have shown that levels of consumer satisfaction increased when services were provided by the worker cooperatives (Bau & Harrington, 2003; Whitaker, 2002; Waushara County Department of Human Services, 2003). There are also examples of worker cooperatives working closely with CILs that advocate for people with disabilities. For example, Liberty Resources, a CIL in Philadelphia, is the largest contractor of the services of HCA, one of the worker cooperatives.

Worker cooperatives have used funding sources for training that have not been tapped by consumer cooperatives. A number of worker cooperatives have received workforce development funding from private foundation and public sector programs to train

low-income people to become PAS workers. For example, CHCA has received funding for workforce development from the Community Service Society, the Charles Stewart Mott Foundation, the Ford Foundation, the Robin Hood Foundation and the Paraprofessional Healthcare Institute, among many others. This funding has enabled CHCA to provide extensive 4- to 6-week training programs to low-income workers, before they begin delivering services (Inserra, Conway, and Rodat, 2002). Worker cooperatives are able to obtain workforce development monies, because they have successfully trained people who previously received public assistance and enabled those people to become employed and self-sufficient. In recent years, worker PAS cooperatives have received increased funding from religious organizations to train workers, and these religious organizations have emerged as key funding sources for the worker cooperatives. (Stu Schneider, personal communication, September 3, 2007). While the model of training used by worker cooperatives might not be appropriate for consumer-run cooperatives, those who are developing new cooperatives might want to think about workforce development issues and possible funding sources related to creating a more skilled and well-paid PAS workforce. Programs that train people with disabilities to be PAS workers (like the one described in the section on LEAP) might be eligible for workforce development funding.

Worker cooperatives have used organizations and funding sources that are based on the agricultural model of cooperatives. Worker cooperatives are more closely tied to experts and funding sources that are based in the traditional agricultural model of cooperatives. For example, worker cooperatives have received funding from the U.S. Department of Agriculture and have been publicized in reports and publications geared to others who participate in cooperatives (Bau & Harrington, 2003; Waushara County Department of Human Services, 2003). In order to develop more consumer-run PAS cooperatives, it may be useful for agencies and organizations that oversee and promote disability services to develop partnerships with agencies and organizations that promote traditional agricultural cooperatives. PAS cooperatives require expertise and skills in both the disability services and cooperatives, lending themselves to partnerships.

Findings and Conclusions

ODEP asked the Center for Personal Assistance Services (CPAS) to conduct a literature and resource review and identify promising practices and funding sources for PAS cooperatives. The primary goal of this investigation was to see how these cooperatives could support PAS, especially in the area of employment. The initial literature and resource review suggested that the cooperative model had promise as a method of delivering PAS. However, a closer examination revealed only a few examples of successful consumer-directed PAS cooperatives in the United States. In fact, many were not pure cooperatives, but rather organizations with cooperative features. In the United States, there are a number of strong and viable worker cooperatives. In Europe, there are long-standing models of self-sufficient consumer cooperatives that have been providing service for decades. One reason for the difference is that people with disabilities receive much higher levels of federal funding for PAS in Europe, compared to current levels in the United States.

The descriptions in this report detail the history and practices of a handful of small cooperative or "cooperative-like" organizations providing PAS to promote the self-determination of their members. In all of them, ten percent or fewer members are using the cooperatives' PAS services in order to work or to find employment. In fact, employment was not usually a primary goal of the existing PAS cooperatives, because the individuals' survival needs took precedence. Consumers were not able to even think about working, until they had reliable PAS supports in place at home, a phenomenon people called the "progression of PAS." They viewed employment as the "next frontier" for some working-age people, with participation in the cooperatives possibly facilitating their moves toward employment. These observations build the case for employment supports to facilitate PAS consumers' moves toward employment. The people who told us about their cooperatives saw a great deal of potential for the PAS cooperatives to support employment. They, nevertheless, thought it unlikely that employment would naturally emerge as a major goal of cooperatives, unless it was an explicit focus and goal from the beginning.

The following findings, based on our review of existing cooperatives, could assist in building successful PAS consumer-directed cooperatives. We include findings about the advantages of consumer PAS cooperatives, current and potential funding for consumer PAS cooperatives, and findings for organizations that are considering starting PAS cooperatives.

Advantages of Consumer PAS Cooperatives

- **Consumers have gained self-confidence and self-determination through participating in the cooperative.** In every cooperative, members reported becoming more self-sufficient, confident, and able to participate more fully in community life through participation in the cooperative. The members felt they profited not only from the services they received but also from a sense of community and support provided by the cooperative. They pointed to close personal relationships that developed among both consumers and workers as, perhaps, the most important value of the cooperative.

- **PAS cooperatives allow consumers the right to choose their workers.** The people we talked with believed that consumer choice, rather than Medicaid policy, should dictate the type of provider. Cooperatives are an organizational structure that can allow family members to participate as PAS providers when a consumer chooses that option. In some states, Medicaid policies changes are needed to allow family members as providers when the consumer so chooses.
- **PAS cooperatives focused on workplace PAS could be an essential resource for PAS users who are working or would like to work**. Consumers often have difficulty stretching their PAS resources to cover their personal care needs at work, especially when this involves small amounts of time throughout the day. Because consumers must pay for the time and travel and factor in their own work schedules, they found it difficult and expensive to use their regular PAs to cover their personal care needs at work. People we talked with suggested that PAS cooperatives that were specifically designed to cover work could be an important resource, along with increased funding to support PAS at work.
- **Cooperatives are a potential model for delivery under existing programs of consumer-directed care and Medicaid Buy-In services.** People involved in cooperatives stressed that that they can serve as viable models for service delivery, especially as more states are introducing consumer-directed care options under Medicaid waivers and participating in Medicaid Buy-In programs.
- **Cooperatives can train people with disabilities to be PAS workers for others in the cooperative**. Some of the cooperatives have developed training for people with disabilities, to provide services to others with disabilities in the cooperatives. This model has the potential to develop job skills and experience and provide new employment opportunities for people with disabilities.

Findings About Current Funding of PAS Cooperatives

- **Generating capital or startup funding was the biggest challenge of PAS cooperatives**. Everyone we talked with mentioned startup funding as the major hurdle for consumer-run cooperatives. Costs of liability insurance and delays in reimbursement made it essential for cooperatives to build up adequate funds before initiating services.
- **However, startup costs for consumer-run cooperatives were relatively modest, compared to many service programs**. Groups were able to successfully establish cooperatives and cooperative-like organizations with startup funds ranging from $25,000 to $75,000 per year.
- **Cooperatives have developed by using a range of funding options**. They include private sources, such as insurance and service fees, membership fees, and public and private grants.
- **State developmental disabilities councils were the most frequent sources of startup funding for consumer-directed cooperatives.** Cooperatives and cooperative-like organizations that we found in the United States were most likely to get their startup funding from the developmental disability councils in their respective states. Nevertheless, these cooperatives were not limited to serving only people with developmental disabilities. Once the cooperatives were

started, they sought funding under a variety of different waivers and private pay sources to serve cross-disability populations.

- **Private foundations were another source of funding.** Existing cooperatives also received funding from local foundations. This usually occurred after they had received initial funding from other sources, and the foundation funding was sometimes tagged for a specific purpose such as providing health care for PAS workers. A national foundation, the Robert Wood Johnson Foundation, also funded efforts to start PAS cooperatives in the 1990s, but those efforts were not successful.
- **Centers for independent living and other disability organizations initiated and provided support for consumer-run PAS cooperatives**. CILs were often the primary initiators or partners in initiating the PAS cooperatives. CILs networked with a variety of organizations, located funding sources, provided staff expertise, and often provided low- or no-cost rent to the PAS cooperatives.
- **Consumer-directed cooperatives were not funded by traditional agricultural cooperatives sources, but workers cooperatives did tap those sources.** None of the consumer-directed cooperatives that we interviewed had received funds from the U.S. Department of Agriculture (USDA), but a number of worker cooperatives had gotten startup funding from USDA.
- **Worker cooperatives also utilized workforce development funding to train workers.** The worker-owned cooperatives often relied on private and public workforce development funding to provide extensive programs that trained low-income and unemployed people to become PAS workers. Consumer-run cooperatives have not applied for these funds, in part because their training philosophy is based on consumers training their own PAs. Nevertheless, there may be opportunities for consumer-run cooperatives to seek new funding sources for training workers that are compatible with independent living philosophy.
- **Religious organizations have emerged as a funding source for worker cooperatives**. In the past few years, worker cooperatives have received funds from both Catholic and Presbyterian organizations to improve the long-term care workforce. Consumer PAS cooperatives may wish to explore partnerships with worker cooperatives or other possibilities for funding from similar organization.

Findings for Organizations that are Considering Starting PAS Cooperatives

- **Cooperatives need time to get established**. Allow adequate time to startup and establish a PAS cooperative. The people we talked with generally agreed that starting up a cooperative required at least two years from first meeting to beginning of service delivery. At least five to seven years of startup funding was necessary for cooperatives to have a good chance of becoming self-sustaining.
- **Both large and small cooperatives have advantages.** The ideal size of a cooperative is still an open question. All of the consumer cooperatives we found in this country were small, fewer than 40 people, and some were organized into even smaller self-governing subunits of 4-9 consumers. Many who had started consumer cooperatives felt strongly that the small, intimate nature of their

cooperatives was the main strength of the programs, creating a sense of community and connection. However, larger consumer PAS cooperatives, in European countries, and worker PAS cooperatives, in the United States, have been sustained over decades, suggesting that economies of scale may also provide advantages. Small cooperatives may need assistance in regularly and actively networking, allowing for easier exchange of information and problem solving. This may allow for maintaining the benefits of small size, while gaining strength in numbers and sharing resources.

- **PAS cooperatives require expertise in cooperative structures and service delivery**. On-going and expert technical assistance related to establishing and maintaining a cooperative is absolutely essential. Organizations should take advantage of existing manuals and other resources on PAS. Some of the cooperatives have developed resources for their members (LEAP, 2007; Ohio Developmental Disabilities Council, 2005).
- **Business planning expertise is important.** A business plan and expert financial guidance are equally essential. Cooperatives that failed often cited a lack of expertise and experience with business planning as a reason for their failure. Even successful cooperatives wished they had developed business plans much earlier. Cooperatives that serve as financial intermediaries especially need solid business plans, as well as contingency plans for alternative scenarios. The people we spoke with mentioned the importance of an expert bookkeeper, assistance with board training and development, and other non-profit development.
- **Developing alliances with people in government and related programs is critical.** All of the people we talked with agreed that it is essential to know the "players" in state and local government and programs related to PAS. Differing Medicaid waivers, social service programs, and political climates make this especially challenging. They also thought that having support from key individuals at the state and local level is critical to success.
- **Base all cooperative-related activities on consumer choice.** Cooperatives should be based on consumer choice. Although careful attention to financial planning is essential, the social goals of cooperatives are equally vital. Consumer-directed PAS cooperatives must have mission statements and bylaws that uphold the fundamental rights of consumers to determine their lives and control their services. CILs took the lead in developing many of the cooperatives and cooperative-like organizations investigated, all of which embraced consumer choice.
- **Recognize workers and consumers as participants in cooperatives**. Promote the cooperative model of both consumers and workers as participants in the cooperative, while retaining independent living principles as primary. One successful cooperative had the stated goal of improving wages and benefits for workers, a goal that has been achieved through offering comprehensive health benefits and higher-than-prevailing wages. In that cooperative, workers are members of the board of directors and have a voice in governance. People in other consumer-controlled cooperatives remarked that active involvement of PAS workers was more essential than they had first realized. In one cooperative, for example, consumers themselves lobbied for joint training of consumers and

workers in consumer direction and control rather than the separate trainings originally envisioned, and all parties agreed that the joint trainings were a success. However, successful European models do not use joint governance.

- **Existing worker cooperatives may provide solutions to barriers facing consumer cooperatives.** For example, people in consumer-controlled cooperatives mentioned lack of funds for training PAs as a problem for their cooperatives. In addition to first aid and CPR training, which are often required by funders, more advanced training was seen as important for both worker and consumer safety. Consumer-run cooperatives may want to look at ways in which worker-run cooperatives have solved these issues: A number of worker cooperatives have successfully tapped funding sources for training home health workers.

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Appendix I
Current PAS Cooperatives

I. Consumer-directed cooperatives *(described in detail in the report)*

Bohling Inc.

Holly Bohling, Vice President
P.O. Box 22120
Phoenix, Arizona 85028
Phone: (602) 404-7334
Fax: (602) 953-9312
E-mail: hbohling@cox.net
Web site: http://federatedhsc.coop
Additional information at: http://www.bohlinginc.com

Bridge to Recovery Independent Network South (BRINCS)

Theresa Walczak
530 N. Waterloo Street
Jackson, MI
49201-1743
Phone: (517) 789-9515
Fax: (517) 789-9575
E-mail: theresaw@Tds.net
Web site: (none)

Linking Employment, Abilities & Potential (LEAP) PAS Cooperative

Katharine Foley, LSW, Program Director
Linking Employment, Abilities & Potential (LEAP)
11607 Euclid Avenue, Cleveland, OH 44106
Phone: (216) 229-3029
Fax: (216) 229-9640
E-mail: kfoley@leapinfo.org
Web site: http://www.leapinfo.org/Home.asp

Partners in Personal Assistance

Colleen Clancy, Administrative Coordinator
1100 N. Main Street, Suite 117, Ann Arbor, MI 48104
Phone: (734) 214-3890
Fax: (734) 214-6640
E-mail: info@annarobrppa.org
Web site: http://www.annarborppa.org

Stockholm Cooperative for Independent Living (STIL)

Adolf Ratzka, Member and founding chair
Peterséns Väg 2,
127 41 Stockholm - Skärholmen, Sweden
Phone: +46-8-506-221-50
Fax: +46-8-506-221-70
E-mail: admin@independentliving.org
Web site: http://www.independentliving.org/docs3/stileng.html
Additional information at: http://www.stil.se/viewpage.php?page=25

Tennessee Microboards Association, Inc. (TMA)

Ruthie-Marie Beckwith, PhD, Executive Director
1509 Van Cleve Lane
Murfreesboro, TN 37129
Phone: (615) 898-0300
Fax: (615) 904-0308
E-mail: empfanatic@aol.com
Web site: http://www.tnmicroboards.org

ULOBA Cooperative on Personal Assistance

Tove-Anita Moen Flauum, Regional Manager
Pb. 2474 Strømsø, 3003 Drammen, Norway
Phone: +47 32 20 59 10
Fax: +47 32 20 59 19
E-mail: tove-anita.moen.flaaum@uloba.no
Web site: http://www.uloba.no/templates/Page.aspx?id=223

II. Worker-directed cooperatives *(*Described briefly here, using information supplied by Stu Schneider of Paraprofessional Healthcare Institute and information available on the cooperatives' websites. Worker-directed cooperatives are not the primary focus of this report.)

Cooperative Home Care Associates (CHCA)

349 East 149th Street, 5th Floor
Bronx, NY 10451
Phone: 718/993-7104
E-mail: mailto:mail@info.chcany.org
Web site: http://www.chcany.org

Cooperative Home Care Associates (CHCA)—the nation's largest worker-cooperative—is located in the South Bronx community of New York City (NYC) and currently employs over 1,000 home health aides as well as 50 administrative staff members. The Community Service Society, a large and well-endowed non-profit organization in NYC, created CHCA in 1985.

CHCA earns nearly $20 million in annual revenue by providing home care services to individuals through Medicaid and Medicare programs. CHCA also staffs an enhanced four-week paraprofessional training program that enrolls over 300 low-income participants each year.

Home Care Associates (HCA)

1315 Walnut Street Suite 832
Philadelphia, PA 19107
Phone: 267/238-3213
Fax: 215/735-0644
Web site: http://www.homecareassociatespa.com

Home Care Associates (HCA), located in Philadelphia (PA), employs nearly 160 home health aides. HCA was created in 1993 by the Paraprofessional Healthcare Institute as the first replication of CHCA. HCA earns most of its $5 million in annual revenue by providing home care services to individuals with physical disabilities through Medicaid-waiver programs. Liberty Resources, a Center for Independent Living that works with people with disabilities, is currently the largest contractor of HCA's services. HCA also operates an enhanced four-week paraprofessional training program that enrolls nearly 100 low-income participants each year.

Cooperative Care

P.O. Box 620
402 East Main Street
Wautoma, WI 54982
Phone: 920/787-1886
Fax: 920/787-1888
Web site: http://co-opcare.com/

Cooperative Care, located in Wautoma in rural Wisconsin, currently employs 85 home health aides, all of whom are worker-owners. Cooperative Care was created in 2001 when direct-care workers employed as independent contractors were organized into a worker-owned cooperative. Before the formation of the cooperative, the workers were employed as independent caregivers by individual consumers who received publicly funded PAS services. The Waushara County Department of Human Services supported the formation of the cooperative, partly as a proactive approach to dealing with fears about liability issues triggered when an individual independent worker was injured on the job. The cooperative entered into an 18 month, $850,000 contract with the county, which allowed the PAS providers to continue to provide services to the same consumers. After their employment by Cooperative Care, worker-owners received a significant increase in pay and a comprehensive benefits packages including: paid vacations and holidays, travel reimbursements, and health insurance.

Circle of Care Cooperative

3701 East Evergreen Drive, #200-101
Appleton, WI 54913
Phone: 920/968-2273
Web site: http://www.circleofcarecoop.org/

Circle of Care Cooperative, located in Appleton, WI, currently employs 38 PAs—all of whom are member-owners—and is poised for growth in a market of 600,000 people residing in both urban and rural areas. Circle of Care Cooperative opened for business in April 2006, with funding and technical assistance provided by CAP Services (a community action agency), USDA Rural Development, and North Country Cooperative Development Fund. The Circle of Care Cooperative mainly serves private pay clients (individuals who use their own money to pay for needed care) but has also entered into county contracts for publicly financed care to low-income individuals.

Manos Home Care

4173 MacArthur Blvd., Suite C
Oakland, CA 94619
Phone: 510/336-2900
Fax: 510/336-2903
Web site: http://www.manoshomecare.com

Manos Home Care, located in Oakland, CA, currently employs 200 home health aides, although most are in part-time positions. Manos is structured as a mutual benefit corporation where workers represent most members on its Board of Directors and receive profits as "additional compensation checks." Kevin Rath created Manos as a social enterprise with lead funding from the Irvine Foundation. Manos currently earns nearly 75 percent of its revenue from serving private-clients throughout San Francisco's East Bay area and 25 percent from providing respite care to caregivers of children with disabilities.

I Am Unique Special Care and Case Management

4318 Bland Road.
The Flagship Bldg
Raleigh, NC 27609
Phone: (919) 981-0790
Fax: (919) 981-0135
E-mail: kcampbell@iamunique.coop
Web site: http://www.iamunique.coop/

I Am Unique Special Care and Case Management is a skilled nursing cooperative that employs RNs and LPNs. Established in 1994, I Am Unique is the first home care cooperative in North Carolina, and it was modeled after CHCA in New York. In 2004, 90 percent of the 24 consumers served by this organization used ventilators and required intensive (often 24-hour) care. At that time, the organization had 77 worker members.

Appendix 2
Funding Sources

I. Sources that have funded consumer PAS cooperatives

Ann Arbor Area Community Foundation

201 S Main Street
Ann Arbor, MI 48104
Phone: (734) 663-0401
Fax: (734) 663-3514
E-mail: info@aaacf.org
Web site: http://www.aaacf.org/

Center for Medicare and Medicaid Services (CMS)

Community-Integrated Personal Assistance Services and Supports (CPASS), and other Real Choice Systems Change Grants
7500 Security Boulevard
Baltimore, MD 21244-1850
Web site: http://www.cms.hhs.gov/RealChoice/01_Overview.asp#TopOfPage

More information on applying for the grants is available at:
http://www.cms.hhs.gov/RealChoice/03_GrantResources.asp#TopOfPage

and

http://www.cms.hhs.gov/RealChoice/02_WhatsNew.asp#TopOfPage

(These grants are made to states in collaboration with stakeholders. They have been used to fund consumer-directed PAS cooperatives in Arizona—described in the section on Bohling Inc.—and Michigan—described in the section on BRINCS.)

Illinois Council on Developmental Disabilities

101 W. Randolph, Suite 10-600
Chicago, Illinois 60601
Phone: 312-814-2080
Fax: 312-814-7141
Web site: http://www.state.il.us/agency/icdd/
Project Web site: http://www.managingtheartofliving.org/

Michigan Association of Community Mental Health Boards

426 South Walnut
Lansing, MI 48933
Phone: (517) 374-6848

Fax: (517) 374-1053
Web site: http://www.macmhb.org/

Ohio Developmental Disabilities Council

8 E. Long Street, Suite 1200
Columbus, OH 43215-2931
Phone: (614) 466-5205
Fax: (614) 466-0298
Contact: Fatica Ayers
E-mail: Fatica.Ayers@dmr.state.oh.us
Web site: www.ddc.ohio.gov

Robert Wood Johnson Foundation

P.O. Box 2316
College Road East and Route 1
Princeton, NJ 08543-2316
Phone: (877) 843-4653
Web site: http://www.rwjf.org/

Tennessee Council on Developmental Disabilities

Parkway Towers, Suite 130
404 James Robertson Parkway
Nashville, Tennessee 37243-0228
Phone: (615) 532-6615
Fax: (615) 532-6964
Contact: Errol Elshstein
E-mail: Errol.Elshstein@state.tn.us
Web site: http://www.state.tn.us/cdd/

II. Examples of sources that have funded worker PAS cooperatives

Catholic Campaign for Human Development (CCHD)

CCHD supports an Economic Development Program, which funds organizations that create high-quality jobs and supportive workplaces as well as help low-income individuals develop assets.

As the first step of CCHD's application process, organizations complete an eligibility quiz. For more information about specific questions, you can identify a field representative serving your specific area at: http://www.usccb.org/cchd/fieldreps.shtml

3211 4th Street, N.E.
Washington DC 20017-1194
Phone: (202) 541-3000
http://www.usccb.org/cchd/edgengrant.shtml

Community Action Partnerships

1140 Connecticut Avenue, Suite 1210
Washington, DC 20036
Phone (202) 265-7546
Fax (202) 265-8850
E-mail: info@communityactionpartnership.com
Web site: http://www.communityactionpartnership.com/default.asp

Mutual Service Cooperative (MSC) Fund

Managed by the Cooperative Development Foundation, MCS currently supports cooperative development that enhances the quality of life for seniors living in rural America.

Cooperative Development Foundation

1401 New York Ave, NW Suite 1100
Washington, DC 20005-2160
Phone: (202) 638-6222
Fax: (202) 638-1374
Web site: http://www.cdf.coop/msc_fund/index.htm

If you have specific questions about the application process for the MSC Fund, please contact Ellen Quinn at equinn@cdf.coop or leave a voice mail (with your specific question) at (202) 383-5474.

Presbyterian Committee on the Self-Development of People

This entity supports poverty-alleviation initiatives that are presented, owned and controlled by low-income people who will benefit directly from its work.

Headquarters:
100 Witherspoon Street
Louisville, KY 40202
Phone: (888) 728-7228 ext. 5791
Web site: http://www.pcusa.org/sdop/applicationprocess.htm
E-mail: sdop@ctr.pcsusa.org
For specific questions, please direct inquiries to Marina Zaldivar

USDA Rural Development

Room 5045-S
Mail Stop 3201
1400 Independence Avenue SW
Washington, DC 20250-3201
Phone: (202) 690-4730
TTY: (800) 877-8339
Fax: (202) 690-4737
Contact: All applications for loans and grants are handled at the local level.

Web site: http://www.rurdev.usda.gov/

Wisconsin Department of Health and Human Services

Department of Health and Family Services
1 W. Wilson Street
Madison, WI 53703
Phone: (608) 266-1865
E-mail: webmaster@dhfs.state.wi.us
Web site: http://dhfs.wisconsin.gov/

Appendix 3 Cooperatives Resources (Experienced in PAS Cooperatives)

Experience with consumer PAS cooperatives

Bohling Inc.

Holly Bohling, Vice President
P.O. Box 22120
Phoenix, Arizona 85028
Phone: (602) 404-7334
Fax: (602) 953-9312
E-mail: hbohling@cox.net
Web site: http://federatedhsc.coop
Additional information at: http://www.bohlinginc.com
(See section of this report on Bohling Inc. for more details on role in developing consumer cooperatives.)

NASCO (North American Students of Cooperation)

P. O. Box 7715
Ann Arbor, MI 48107
Phone: (734) 663-0889
Fax: (734) 663-5072
Contact: Jim Jones, Senior Director of Development and Property Services
Phone: (734) 657.8471
E-mail: jim@nasco.coop
Web site: http://www.nasco.coop/front
(See section on Partners in Personal Assistance for more details on role in developing consumer cooperatives.)

Tennessee Microboards Association, Inc.

Ruthie-Marie Beckwith, PhD, Executive Director
1509 Van Cleve Lane
Murfreesboro, TN 37129
Phone: (615) 898-0300
Fax: (615) 904-0308
E-mail: empfanatic@aol.com
Web site: http://www.tnmicroboards.org
(See section on Tennessee Microboards, Inc. in this report for more details on role in developing cooperatives.)

Experience with worker PAS cooperatives

Paraprofessional Healthcare Institute

349 East 149th Street, 10th Floor
Bronx, NY 10451
Tel: (718) 402-7112
Fax: (718) 585-6852
Contact: Stu Schneider, Workforce Development Practitioner
E-mail: Stu@paraprofessional.org
Web site: http://www.paraprofessional.org/

Wisconsin Rural Development

4949 Kirschling Ct.
Stevens Point, WI 54481
Phone: (715) 345-7615
Fax: (715) 345-766
Contact: Margaret Bau, Cooperative Development Specialist
Phone: (715) 345-7600, ext. 171
E-mail: Margaret.Bau@wi.usda.gov
Web site: http://www.rurdev.usda.gov/wi/index.htm

ICA Group

One Harvard Street, Suite 200
Brookline, MA 02445
Phone: (617) 232-8765
Fax: (617) 232-9545
E-mail: ica@ica-group.org
Web site: http://www.ica-group.org/

CooperationWorks!

P.O. Box 527
Dayton, WY 82836
Phone: (307) 655-9162
Fax: (307) 655-3785
Contact: Audrey Malan, Executive Director
E-mail: cw@vcn.com
Web site: http://www.cooperationworks.coop

University of Wisconsin Center for Cooperatives

230 Taylor Hall
427 Lorch Street
Madison, WI 53706-1503

Contact: Anne Reynolds, Assistant Director
E-mail: info@uwcc.wisc.edu
Web site: http://www.uwcc.wisc.edu/