

Jans, L., & Kraus, L. (2007). *Annotated bibliography of literature on personal assistance service cooperatives*. Center for Personal Assistance Services.

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Altus, D. (1995). *Consumer co-ops: A resource guide for consumers with disabilities*. Final report of the Co-op Access Project, University of Kansas.

This report summarizes the findings of the Co-op Access Project at the Institute for Life Span Studies at the University of Kansas. The National Institute on Disability and Rehabilitation Research (NIDRR) funded the project to examine options for a variety of different kinds of cooperatives to serve people with disabilities, including PAS co-ops. The report concluded that the cooperative model had a strong potential for empowerment and consumer direction among people with disabilities. Consumers with disabilities and independent living staff members who responded to a survey about co-ops expressed a great deal of interest in the idea of cooperatives to provide PAS. The study found that consumer cooperatives were popular in Europe, but that the predominant model in the United States was the worker-owned cooperative. The report notes that worker co-ops also offer benefits to the consumer through better-trained, stable staff who may provide higher-quality services.

In addition to presenting information about PAS co-ops, this report also provides background information on the cooperative movement, and offers descriptions and examples of disability-related housing, food, child care, health care, transportation, credit union, dining, and assistive technology cooperatives. New consumer PAS cooperatives may also benefit from a section on starting a co-op, as well as information on related resources.

Anderson, W. L., Wiener, J.M., Greene, A.M., & O'Keeffe, J. (2004, April). *Direct service workforce activities of the Systems Change grantees*. RTI International.

Retrieved February 12, 2007 from:

<http://www.hcbs.org/files/35/1708/CMSWorkforce.pdf>

In 2001 the Centers for Medicare and Medicaid Services (CMS) awarded Real Choice Systems Change (RCSC) Grants to states and other entities working to improve state long-term care systems. Twenty grantees began one or more initiatives to improve the recruitment and retention of direct service workers. This report focuses on the workforce initiatives of these 20 grantees, with an in-depth look at 7. Some of these models include PAS worker co-ops as a way of addressing workforce retention and creating quality jobs for PAS providers. The report also addresses, to some degree, the ways in which relationships between consumers and workers may impact the feasibility of workers' co-ops. For example, the move toward consumer-directed care may foster worker co-ops, but some consumers' reluctance to share PAS providers may impede the formation of worker co-ops. The report strongly recommends that policymakers, providers, and consumers deal with workforce problems, and those issues may be important for consumer-directed PAS cooperatives to address.

Bau, Margaret and Dianne Harrington. (May/June 2003). *House calls: In-home care givers form cooperative to provide vital service for elderly, disabled in rural Wisconsin.*

Retrieved July 24, 2006 from

<http://www.rurdev.usda.gov/rbs/pub/may03/mayjune.pdf>

Cooperative Care, a worker-owned PAS co-op that provides homemaker services and nursing assistant care to people with disabilities and seniors in their homes, was highlighted in the May/June 2003 issue of "Rural Cooperatives" magazine. The article outlines the demand for in-home care, and the shortage of in-home direct-care workers. The authors then trace the history of Cooperative Care from the initial planning stages in 1999 to the challenges that will meet the co-op in the future. They discuss target population, recent achievements, key individuals and organizations, budget, and media coverage. Although this article is focused on a worker-run cooperative, its description of financing sources and business challenges and how they were overcome may be useful in the development of consumer-run PAS cooperatives.

Bowman, V. (2001). *Home care, home support, personal assistance: The co-operative model in context.* Occasional papers, BCI Institute for Co-operative Studies, University of Victoria, Canada. Retrieved November 2, 2006 from:

<http://web.uvic.ca/bcics/research/pdf/pub-4-12Apr01.pdf>

This report looks cooperative models of economic development as a way to meet the needs of consumers and providers of home care and home support. The report includes case studies of the Stockholm Cooperative for Independent Living (STIL), a consumer-controlled cooperative, and

Cooperative Home Care Associates (CHCA), a worker-controlled cooperative. The report also examines the need for co-ops in the Victoria, British Columbia area, and describes the Home Support Action Group, a local coalition that in 2000 was in the process of starting a Personal Assistance Co-operative Society. These case studies are helpful in providing details about the history, goals, methods of development, services, wages, and lessons learned from these cooperative examples.

Doty, P. (1998). The cash and counseling demonstration: An experiment in consumer-directed personal assistance services. *American Rehabilitation, Summer-Autumn*. Retrieved November 29, 2006, from <http://www.hhp.umd.edu/AGING/CCDemo/Publications/dotyRehab.html>

This report on the "Cash and Counseling" demonstration and evaluation project funded by the Robert Wood Johnson Foundation briefly describes an organization called Concepts for Independence. This was a consumer cooperative in New York City, that was established in 1983 and run by and for people with disabilities. Concepts for Independence served as the employer of record for home care attendants who were hired directly by the consumers. This model was enhanced by 1995 legislation in New York that created the Medicaid entitlement for consumer-directed care.

Glazier, R. E. (2001). The "reinvention" of personal assistance services. *Disability Studies Quarterly, 12 (Spring)*. Retrieved November 29, 2006 from [http://www.dsqsds.org/articles\\_pdf/2001/Spring/dsq\\_2001\\_Spring\\_12.pdf](http://www.dsqsds.org/articles_pdf/2001/Spring/dsq_2001_Spring_12.pdf)

This article reviews the history of personal assistance services and recent moves toward consumer-directed services. It is useful as background information for understanding the roles of advocacy organizations in increasing access to PAS, as well as some of the policy issues that have helped to shape the current context for PAS cooperatives. It makes reference to a consumer-directed PAS cooperative in New York City, "Concepts of Independence." That organization pooled funds and functioned in a manner similar to home health agencies, but was operated by and for consumer members.

International Cooperative Alliance (2006). *What is a cooperative?* Retrieved December 2, 2006 from <http://www.ica.coop/coop/index.html>

ICA is an independent, non-governmental association that unites, represents and serves co-operatives worldwide. Founded in 1895, ICA has 230 member organizations from 92 countries active in all sectors of the economy. Together these co-operatives represent more than 800 million individuals worldwide. This web site provides an overview of cooperatives (co-ops) throughout the world, including a definition of a co-op and examples of member organizations' efforts.

Kahn, K. (2003). Multi-stakeholder coalitions: Promoting improvements in the long-term care workforce. *Better jobs, better care. Issue brief, 1* (1). Retrieved February 16, 2007 from <http://www.paraprofessional.org/publications/BJBCIssueBriefv1n1.pdf>

The article describes coalitions among long-term care provider organizations, workers, and consumers, workers to create changes in the workplace to improve job conditions and work environments for PAS workers and quality of services for consumers. As the author puts it, "The complex interplay of market forces, industry practices, and public policies involved in making such changes means that no single person, organization, or sector can resolve the long-term care labor crisis on its own." The article focuses primarily on PAS worker conditions, but the detailed information about multi-stakeholder coalitions may be useful for PAS consumers seeking more control of their services.

Kahn, K. (2000). *Quality Care Partners: A case study*. Paraprofessional Healthcare Institute. Retrieved February 12, 2007 from <http://www.directcareclearinghouse.org/download/QCPCaseStudy.pdf>

This case study examines the development of Quality Care Partners, a paraprofessional, worker-owned PAS cooperative in Manchester, New Hampshire. Sponsored by three state-level non-profit organizations, and funded by national, state, and local foundations, Quality Care Partners was founded to improve both the quality of jobs for low-income healthcare workers and the quality of PAS services for people with disabilities. The article identifies potential benefits for PAS consumers when PAS worker conditions are improved, including less worker turnover, more reliable services, and better-trained providers. The study documents five general categories of lessons learned in the early development of the co-op, including building strong partnerships, acquiring adequate financing, identifying markets through formal business-market and labor-market analyses, identifying and hiring "social entrepreneurs" as leaders, and developing demand. The case study provides detail on the research and development and startup of the enterprise, which moved from idea to reality in less than three years. Useful descriptions include the relationships among the partners who initiated the cooperative, the market analysis and development of the business plan, the local and state funding mechanisms and amounts of funding for startup, the process of finding a CEO, the gradual transfer of ownership to member-owners and amounts of ownership fees, the training program for PAS workers, and the tensions among the different players within the project. Although this case study focuses on a worker-run cooperative, and some of the services were provided in nursing homes and assisted living facilities rather than to people living independently, nevertheless the lessons learned about setting up a PAS cooperative as a business and acquiring financing may be helpful to cooperatives run by

consumers and those that work for the benefit of both consumers and workers.

Kennedy, J., & Litvak, S. (1991). *Case studies of six state personal assistance services programs funded by the Medicaid Personal Care option*. World Institute on Disability for the Office of Disability, Aging and Long-Term Care Policy, Office of the Assistant Secretary for Planning and Evaluation. Retrieved November 29, 2006 from <http://aspe.hhs.gov/daltcp/reports/casestud.pdf>

This report presents case studies of PAS programs funded by the Medicaid Personal Care Option in six states: Maryland, Massachusetts, Michigan, Montana, Oregon, and Texas. The report discusses attempts to make the programs more responsive to consumers; a consumer cooperative in Maryland was also mentioned in passing.

McNutt, S. (2003). *Partners in personal assistance*. UCP of Michigan. Retrieved November 3, 2006 from [http://www.ucp.org/ucp\\_localdoc.cfm/87/8304/8304/8304-8304/1104](http://www.ucp.org/ucp_localdoc.cfm/87/8304/8304/8304-8304/1104)

This brief web article describes the startup of Partners in Personal Assistance, a Michigan consumer-controlled PAS cooperative. The cooperative was started to allow PAS consumers to have more self-determination, autonomy, and freedom in choosing how to live, work, and play. The main goals of the cooperative are described as providing health care benefits for the PAs and training for both PAs and consumers. The article states that the group's chief goal is to raise PAS to a respected profession and make it a career choice for people wanting fulfilling work. This is an example of a consumer-run cooperative with a strong emphasis on improving conditions for PAS workers.

Michigan Department of Community Health (n.d.) Systems Change proposal abstract. Retrieved November 16, 2006 from [http://www.michigan.gov/documents/Michigan's Real Choice Systems Change Grant Abstract 34822 7.doc](http://www.michigan.gov/documents/Michigan's_Real_Choice_Systems_Change_Grant_Abstract_34822_7.doc)

This proposal abstract summarizes the Consumer Cooperative Initiative that the Michigan Department of Community Health is developing. According to the abstract, this is a "model in which consumers and family members will collectively assume responsibility for their outcomes and take control of the resources needed to achieve them. The Co-op will allow members to design and obtain the services they prefer, with more creativity, responsiveness and cost-effectiveness. This model offers an exciting advancement in systems changes in support of consumer-directed services." Further information about the implementation of the proposal is needed in order to evaluate the outcomes and whether this project was successful.

National Cooperative Business Association (2005). *About cooperatives*. Retrieved December 2, 2006 from <http://www.ncba.coop/abcoop.cfm>

This website defines and describes cooperatives, with an emphasis on US co-ops. Categories of co-ops described include: agriculture, childcare and preschools, economic development, energy, finance and insurance, food, funeral and memorial societies, healthcare, housing, purchasing and shared services, worker-owned, and others. The website also includes statistics on co-ops in the US.

Ratzka, A. (1996). *STIL, the Stockholm cooperative for independent living*. Retrieved June 26, 2006, from <http://www.independentliving.org/docs3/stileng.html>

This article describes a Swedish cooperative, STIL or the Stockholm Cooperative for Independent Living, which was created and managed by people with disabilities to provide personal assistance services (PAS) to its members. This co-op has 160 members and 800 assistants, and has an annual turnover of \$14 million. Background materials provide an understanding of context of the cooperative, including information about the Swedish social welfare system, and national insurance benefits. In STIL, the members with disabilities pool the funds that the national insurance allots to them for PAS services. The cooperative hires the personal assistants, who are supervised by the individual members who use their services. Personal assistance services are provided wherever they are needed, including the workplace. Existing members train new cooperative members in how to manage their PAS, and on-going peer support helps members solve any problems to become even better managers of their own PAS. STIL provides a model for a user-run PAS cooperative that has been adopted throughout Sweden and internationally.

Spillman, B.C., Black, K.J., & Ormond, B.A. (2006, April). *Beyond Cash and Counseling: An inventory of individual budget-based community long-term care programs for the elderly*. Kaiser Commission Issue Paper. Retrieved November 29, 2006 from <http://www.kff.org/medicaid/upload/7485.pdf>

This report reviews state Medicaid activity as of January 2006 in developing individual budget model programs for elderly beneficiaries. It notes in passing that the Human Services Cooperative of Arizona provides services to elderly Medicaid beneficiaries. (Note: This organization originally evolved as a PAS cooperative run by and for parents of children and youth with disabilities; it has since expanded to include other PAS cooperatives.)

Sutherland, K., & Beachy, T. (2004, March). *Innovative co-ops in the social services sector: A research study to benefit people with developmental disabilities and mental illness*. Cooperative Secretariat, Government of Canada. Retrieved November 14, 2006 from [http://www.coop.gc.ca/pub/pdf/socserv-servsoc\\_e.pdf](http://www.coop.gc.ca/pub/pdf/socserv-servsoc_e.pdf)

This report looks at cooperatives to benefit people with developmental disabilities or mental illness. It examines twenty examples of co-ops in many different countries, and provides five in-depth case studies. The report provides a matrix for measuring success and sustainability of co-ops, which includes both social values and financial goals. For long-term success, co-ops must achieve both high social values and high financial viability, which is often a difficult balance. Although this report is focused on housing and employment-related cooperatives more than personal assistance services, the lessons can be valuable for achieving successful PAS co-ops.

Tengstrom, A. (n.d.) Presentation of JAG cooperative of personal assistance. Retrieved November 29, 2006 from <http://www.independentliving.org/docs5/jag.html>

This web article describes JAG, a Swedish PAS cooperative created in 1994 that serves people with intellectual disabilities. This cooperative was inspired by and modeled after STIL, the cooperative described in Ratzka (1996). All of the members have intellectual disabilities, usually as a result of developmental disabilities or head trauma, and many have significant physical disabilities. Due to the nature of their disabilities, the members are generally represented on the board of JAG by their legal guardians. Members also choose "deputy supervisors" who assist in training and supervision of PAs. JAG's member often need 24 hour care and cannot be left alone even briefly; the deputy supervisors are responsible for ensuring the safety and quality care of the members.

US Department of Agriculture (1996.) *How to start a cooperative*. US Department of Agriculture: Rural Business/ Cooperative Service. Cooperative Information Report 7. Retrieved December 2, 2006 from <http://www.rurdev.usda.gov/rbs/pub/cir7/cir7rpt.htm>  
Also available in pdf format:  
<http://www.rurdev.usda.gov/rbs/pub/cir7/cir7.pdf>

This guide describes the basic process of organizing and financing a cooperative business, including the most important elements to consider when forming a cooperative. Earlier versions of this guide emphasized cooperatives of agricultural producers; however, this version includes non-farm cooperative applications such as health care and child care. Although preliminary interviews with members of PAS cooperatives suggest that it is essential to include at least one person with in-depth financial experience in cooperatives, they also recommend that all the member-owners gain a basic understanding of the cooperative model, and information from this guide

could be adapted to provide such an orientation.

Waushara County Department of Human Services. (June 2003). *Cooperative Care: The first year*. Retrieved October 16, 2006, from [http://www.directcareclearinghouse.org/download/CoopCare\\_the\\_first\\_yr.pdf](http://www.directcareclearinghouse.org/download/CoopCare_the_first_yr.pdf)

This evaluation and analysis of the first year of Waushara County's care-worker cooperative is organized into three parts. The first gives a background on Waushara County, its workforce issues, a description of how the cooperative was built, and a discussion on the future of cooperative care. Part two summarizes the results of surveys given to cooperative members as well as their consumers. Part three includes the survey instruments and raw data. PAS consumers expressed high levels of satisfaction with the services provided. This analysis a worker cooperative's business methods and owner-member and customer satisfaction issues may assist in the development of cooperatives that are consumer-driven or designed for the benefit of both consumers and workers.

Wheeler, B., Luce, E., & Coontz, E. K. (2001). *The many faces of consumer-direction: Consumer co-ops for people with disabilities who use personal assistance services*. Final report to Robert Wood Johnson Foundation.

This report provides a "post-mortem analysis" of the reasons for the failure of the California PAS Consumer Co-op project. The project included four PAS cooperative initiatives in both northern and southern California, funded by the Robert Wood Johnson Foundation Independent Choices Program during the period 1997-2000. Although it had been expected that consumer co-ops would be an effective model to promote consumer direction among recipients of In Home Supportive Services (IHSS) in California, none of the four co-ops was successfully established during the three years of the grant. One co-op in San Diego was a "near success," coming close to obtaining a multi-million dollar contract with the county. Factors identified as barriers included consumer reluctance to start or join IHSS co-ops, the disability community's preoccupation with the adoption of the Public Authority, counties' hesitance to implement co-ops, problems with marketing, and others. The report summarizes the lessons learned from the initiatives, including the need for developing leadership and social capital among consumers, the importance of taking into account unique state and local climates in the development of consumer cooperatives, and need for a time period greater than three years to establish a consumer PAS co-op.

Whitaker, J. (2002). *Preventing a "revolving door" workforce: Lessons from the literature*. Bureau of Aging and Long Term Care Resources, Wisconsin Department of Health and Family Services. Retrieved October 16, 2006 from <http://www.dhfs.wisconsin.gov/Aging/Genage/revolvingdoor.pdf>

This article analyzes the causes of high turnover among direct-care workers through a review of literature and research. According to the author, the most promising strategies for reducing turnover are rooted in improving workers' pay and benefits, building opportunities for broader worker participation, and providing meaningful training. The article also provides examples of worker cooperatives, which have been successful in reducing turnover rates. Although these issues are most relevant to worker cooperatives, the analysis of causes of turnover and the descriptions of training issues may be instructive for consumer PAS cooperatives as well.

Whitaker, J., Schneider, S. & Bau, M. (2005, February). *Home care cooperatives: Worker ownership in focus*. Wisconsin Long Term Care Workforce Alliance. Retrieved October 16, 2006 from:

[http://www.directcareclearinghouse.org/download/PageByPage\\_REVISED\\_5\[1\].pdf](http://www.directcareclearinghouse.org/download/PageByPage_REVISED_5[1].pdf)

This paper explores the use of worker-owned home care cooperatives as a strategy that could be used to create a more stable long-term care workforce. In the paper, the authors highlight three different models of worker-owned home care cooperatives: the job-training model, the cooperative conversion model, and the multi-stakeholder model. The authors argue that home care cooperatives offer workers a number of benefits including: living wage jobs, a democratic organizational culture, and the opportunity to take part in quality care giving. Since there are many more examples of worker-run than consumer-run PAS cooperatives, the description of different ways of setting up worker cooperatives, and the successes and failures of those models may assist consumer cooperatives in developing sustainable practices.