

Books To Share

Nickled and Dimed... On (Not) Getting By In America

By Barbara Ehrenreich

This is a work of research, but also a first-person account by the author who went undercover as a working American in four job settings. Two are of particular interest since one was in Maine (and was reportedly the hardest dollar she earned), working as a day maid. A second job of particular interest was as a direct care worker in a nursing home. She earned lousy wages, and soon resigned due to the huge responsibility and hours of being "frozen" in low pay and little support. (Sound a little like a job you or a colleague may have or have had?)

This book is a must-read and takes a close look at how people struggle and try to survive on 8 or 9 dollars an hour. This book is a motivator to pull together to improve the workplace conditions for everyone. *(Reviewed by Jane O'Loughlin French)*

The Best Friends™ Approach to Alzheimer's Care

by Virginia Bell and David Troxel

"Helping patients and families cope with Alzheimer's Disease is one of the major challenges for our society. Bell and Troxel have provided an outstanding guide for anyone involved in the care of individuals with Alzheimer's disease. The Best Friends™ method is an innovative, sensitive and unique approach that can greatly improve the quality of life for patients with the most devastating disease known to man." -William R. Markesbery, MD. Director, Alzheimer's Disease Research Center and Sander-Brown Center on Aging, University of Kentucky
(Reviewed by Roberta Record)



How to Reach Us

This newsletter has been produced for Maine PASA. Contributors include Elise Scala, Lisa Marie Lindenschmidt, Jocelyn Barrett and Maine PASA members.

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Maine PASA

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The Maine Personal Assistance Services Association is a coalition of people employed to provide assistance to persons with disabilities and elders. Maine PASA is organized to empower workers, to build opportunities, to respect human dignity and to improve the quality of our jobs.

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August 2004

**Excellence in Long Term Care Conference
September 27, 2004, 8:00 AM to 3:30 PM
Augusta Civic Center**

Save the Date and Set Your Calendar!

Maine PASA is pleased to join the sponsors of the "Excellence in Long Term Care Conference" to announce the upcoming Fall Event to recognize direct-care and direct support work and staff. This is the second annual event sponsored by the Long-Term Care Ombudsman Program, Maine Health Care Association, and First Atlantic Corporation for recognizing caregivers in residential care, and this year offers an expanded program that is co-sponsored by the Home Care Alliance of Maine and Maine PASA. The program will feature Dr. Robyn Stone, Executive Director of the Institute for the Future of Aging Services, a national researcher and author on health care and aging policies and the links between quality jobs and quality care. The day will offer a selection of workshops on topics of interest to direct-care and direct support staff that includes Ed Latham (back by popular demand) and a special presentation by the Glenridge Rehabilitation and Nursing Care staff on their innovative programs and organizational changes. A Maine PASA reception hosted by the Board of Directors will be held immediately after the conference.

This exciting event is an opportunity for direct-care, direct support and personal assistants in Maine to gather, to enjoy programs that will enrich their work, and to be recognized for the important work they do. We request that employers support their staff to attend this program and that staff who can attend take notes and share the information with their coworkers who be covering the schedule.

Maine PASA Reception Planned: September 27th, 4 p.m.-6 p.m.

The Board of Directors will host an open reception for Maine PASA members following the conference at the Augusta Civic Center. This reception will be a great opportunity to meet other Maine PASA members, to reflect on the day's events and to hear about Maine PASA's activities. Maine PASA, under the guidance of the Board and the membership started as an idea and is blooming into an organization that cares about direct care and support and the people employed to provide these services. This event is a time to celebrate this growth and an opportunity for current and future members to let the Board know what opportunities you want to see and what issues you want addressed. If you would like more information or need accommodations, please call Maine PASA (see "How to Reach Us" on last page).



\$CHOLAR\$HIP\$!

10 scholarships will be available for home care employees to attend the Fall Event. Call Maine PASA. (See "To Reach Us" on back page.) Scholarships will cover the registration fee (\$20) and are available through Maine PASA with the support of the event sponsors on a first-come-first-serve basis.

Call For Nominations!

Watch the mail! The Long-Term Care Ombudsman Program is sponsoring the second annual "Excellence in Long Term Care Award" and is mailing the nomination information to employers. Please consider nominating the outstanding direct-care and direct support staff in your organization for this special recognition. For more information, contact the Maine Long-Term Care Ombudsman Program at (800) 499-0229 (voice/TTY) or email them at MLTCOP@maineombudsman.org. Watch for the August deadline date.



Maine PASA Updates

Maine PASA Developments

Maine PASA is setting the stage for its future as a non-profit, tax-exempt organization. The Board of Directors has been meeting regularly to guide this transition process. The position of Executive Director will be established along with a business plan to continue the work of developing the Association, its membership and to help accomplish Maine PASA's goals.

Get Acquainted Meetings Draw Active Members and Offer Continuing Education

Meetings in Portland, Augusta and Bangor offered members the chance to get together and to discuss a topic of interest to their work. Sue Levandoski, RN and Master Trainer for the Best Friends™ Approach to Alzheimers Care, presented two sessions to highlight the value of knowing your client/consumer. Mary Lee, a training coordinator with OHI in Bangor, presented with co-worker Duane Hall on the topic of working with consumers with high physical needs. Future meetings are being planned and Maine PASA Chapters in Brewer/Bangor and Augusta have been started. For more information, please call the Maine PASA (see "How to Reach Us" on last page) or check out the Events page on www.maine-pasa.org.

Maine PASA to Attend DCA National Conference

The Direct-Care Alliance is a national organization working to bring consumers, workers and concerned providers together to pursue a goal of broad-based reforms to ensure a stable, valued, and well-trained direct-care workforce. On September 18th representatives from across the country will gather for the DCA event, "Building Unity for Valued Workforce" – and Maine PASA has been invited to present! Maine PASA members will be presenting two workshops and a poster session and participating in the pre-conference activities. The program will feature speakers and presentations, including a live performance of Heartwork. For more information, go to www.directcarealliance.org.

Donations to assist for Maine PASA members with travel are needed. Please contact Maine PASA (see "How to Reach Us" on last page).

Maine PASA to Participate in New Consumer Directed Work Group

Maine PASA will participate in a workgroup to identify strategies for improving services and to develop an intake system for consumers seeking assistance in Maine. The workgroup will also respond to the Legislature's request for a joint review and report to expand program eligibility to include consumers who use a surrogate to perform management tasks. A Maine PASA representative will attend the meetings, and participate in the discussion and development of recommendations to be presented on January 1, 2005. The purpose of the group was outlined in the first meeting, July 28th: to involve stakeholders in a process to determine and make recommendations to Commissioner Nicholas.

Grant News

Grant Funds for Alzheimer's Care Will Support Maine PASA Training

Maine PASA will receive funds to support training activities through a grant recently awarded to the Maine Department of Human Services, Bureau of Elder and Adult Services. This grant will increase access to an array of services provided to caregivers of people with Alzheimer's in rural Maine through a collaboration between providers within Maine's Home and Community-Based Care System (HBCS), the Aging Network, and Real Choice System Change Initiatives. The project will expand the pilot caregiver companion program to rural counties and add mental health, end of life care and hospice referral services for clients/families affected by Alzheimer's served by the HBCS and Area Agencies on Aging.

Maine PASA Members Provide Input on Real Choices Grant

The primary goal of Independence Plus, a federally funded grant project in Maine, is to ensure that choice and control are expanded for persons with mental retardation or autism. IP has extended the opportunity for Maine PASA members to participate in the grant workgroup. The new IP waiver program developed through this grant will ensure that consumers and families have sufficient information, training and support to manage their own services and supports as participants in the new program.

Report Summarizes Real Choices Systems Change Workforce Initiatives

June 25, 2004: A report summarizing 20 workforce initiatives funded by Real Choice Systems Change (RCSC) grants calls the initiatives "a step forward in addressing the shortage of qualified direct service workers who can provide high quality care." The activity is divided into five categories:

- recruitment efforts;
- extrinsic rewards such as wages and health benefits;
- training and career ladders;
- changes in the organizational culture that workers experience in their jobs; and
- systems administration and planning.

Initiatives include developing worker associations, paying college students to provide backup consumer-directed services, and making affordable healthcare insurance available to workers. "Workforce issues, which these grantees are addressing, are only slowly being acknowledged as a very serious problem plaguing our long-term care systems," the authors conclude. "A concerted strategy is needed to address workforce problems in states because no single effort is likely to provide the solution to the problem." To read the report, which was prepared for the Centers for Medicare and Medicaid Services by RTI International, go to: <http://www.hcbs.org/>.

**Check out the Maine PASA website!
www.maine-pasa.org**

Maine Updates

Maine Joint Advisory Council Report by Roberta Record

The Department of Corrections has a new role in the future: caring for our Alzheimer's elders who may break the rules in the community and unintentionally hurt others. Our Maine police academies will be training police personnel to identify and help elders with dementia and Alzheimer's. In the training programs, police officers will need to know the community members, know who is violent and who is not, and work towards problem solving – instead of relying on traditional methods of punitive justice. Hopefully, our police will soon be better informed and our elders will be treated with dignity.

Budget Cuts and the Property Tax Cap

On November 2nd Maine voters will be asked "Do you want to limit property taxes to 1% of assessed value?" Whether or not you currently pay property taxes, you probably use municipal services like police, trash and plowing services, perhaps the library and the public schools. This statewide vote, if approved, will reduce the amount of property tax many home owners and businesses pay to their towns and cities. The reductions in payments will save some tax payers money and will effectively reduce the tax revenues of most towns/cities. The decreased income will directly impact the town's ability to pay for services. Local services that cannot be cut will need to be covered by the state budget. The effect will be that Medicaid services could be in more trouble.

A statewide group called the Elder Issues Partnership, comprised of advocates and service providers for elders, is organizing a campaign to educate the public on how the tax cap vote will impact services for elders in Maine. Maine PASA recommends that you stay informed on the issues, the choices, the options and the consequences. Please check listings for the Maine Center for Economic Policy, www.mecep.org, and your local paper, www.Mainetoday.com, for more information - and be sure to ask the questions about how local and Medicaid funded services for the elderly and other vulnerable citizens will be affected by the vote.

New Department: DHHS Open for Business July 1st

The creation of the Department of Health and Human Services (DHHS) became official, following the consolidation the Departments of Human Services (DHS) and Behavioral and Developmental Services (BDS). The commissioner is Jack Nicholas. Governor Baldacci, who introduced the legislation creating DHHS, said that the new department will provide better services for clients and lower costs for taxpayers through improved services, increased efficiencies and improved relationships with community organizations. "My objective is to create a single point of entry, with no closed door, that will improve services for the people of Maine who need them." For more information, contact the Office of Public and Legislative Affairs at 287-1927 (voice), 287-4479 (TTY), or visit <http://www.state.me.us/dhs/>.

Did You Know...

Maine has a MaineCare Option for Workers with Disabilities? This option allows you to earn more and still keep your MaineCare benefits. The intent of the program is to encourage people to go to work, or to work more hours, without risk of losing MaineCare health benefits. This program works in a similar and parallel way to Social Security's Section 1619(b) program, which extends MaineCare benefits for individuals who were receiving SSI cash benefits. This option might help you to start a job, or to work more hours, without losing MaineCare health benefits. Visit <http://www.maine.gov/dhs/beas/work/> for more information.

Maine Awarded Department of Labor Grant to Combat DSP Shortage

The U.S. Department of Labor (DoL) and the American Network of Community Options and Resources (ANCOR) announced a pilot program to build a strong and qualified workforce of direct support professionals (DSPs). The program, announced May 11, 2004, will develop a One-Stop network program model that will provide screened and trained direct support candidates to private providers of community-based facilities for individuals with mental retardation and developmental disabilities. The pilot brings together the key components of the DoL public workforce development network such as One-Stop navigators, state coordinators and representatives from prospective workforce pools, including Native Americans, Job Corps and elder, migrant, young adult and displaced workers. Four states have been selected to test the models: Kentucky, Maine, Arizona and New York. For more information, visit <http://www.ancor.org/dev/Activities/NAC/DoLPilot0504.pdf>.

"All Maine Votes"

An initiative to address access to voting for people with disabilities has organized resources regarding voter registration and absentee balloting, as well as other election-related matters, is available online at http://www.maine.gov/sos/cec/elec/voter_info/index.html. For more information, contact Marcia Cooper at the Disability Rights Center at (800) 452-1948 (voice/TTY) or mcooper@drcme.org.

National Updates

AARP Urges Governments to Support the Direct-Care Workforce

In its current public policy book, AARP recommends several courses of action to strengthen the direct-care workforce. *The Policy Book: AARP Public Policies 2004* sets out the principles guiding all the organization's state and federal advocacy work. In it, the organization calls on federal and state governments to mandate ways of raising wages for direct-care workers and to support "the provision of adequate health benefits, educational opportunities and career ladders to encourage recruitment and retention." For details, go to the Long-Term Services and Supports chapter at <http://directcare.c.topica.com/maacs0uaa8yZZa997MUe/> and scroll down to pages 66-71.

Excerpts from “Common Sense and Patience: Arlene’s Story”

by Jocelyn Barrett, writer, historian, Maine PASA member

“Common Sense and Patience: Arlene’s Story” is the second selection in the Our Stories feature. This series is a collection of stories introducing the voice and experience of direct care and direct support workers. The full stories are published on the Maine PASA website at www.maine-pasa.org with excerpts of each published in our newsletters. As a companion article to Common Sense and Patience, we thought it might also be helpful to include a brief explanation of Consumer-Directed Services. It immediately follows “Common Sense and Patience”.

Arlene and Kevin have spent eleven years building a strong working friendship with one another. Arlene is an understanding and compassionate personal assistant who is a fierce advocate for her friend Kevin. Because they’ve become so familiar with each other, Arlene has taken over much of the supervision and responsibility of the five - and sometimes six - assistants who are providing Kevin with fourteen hours of care per day to help him manage his Multiple Sclerosis and stay in his home. They have faced many challenges together, and both demonstrate the kind of strength of character that can make a Consumer Directed program successful.*

I’ve worked with Kevin for eleven years, and he’s going to be 75 soon. I’m the caregiver who’s been with him the longest. When I first started, Kevin was a very, very active consumer advocate. He was on about five or six different board of directors for different organizations. He’s just a mountain of information. He *loves* politics, and he’s done some very important work in the government. His insight has been absolutely great. I’ve learned things that I’d never even known were out there - like the politics that he keeps track of and the insight that he provides for the different disability programs. He’s a really interesting person to be around.

In February Kevin had a heart attack that did a lot of damage. He is now unable to do 90% of what he used to do by himself. When I first started with him, the work was mostly things like getting his breakfast, it was helping him get dressed, it was helping him do his range-of-motion exercises. It was, if he had any meetings, take him to those meetings. The work’s a lot different now. He’s left with just upper body movement pretty much. He can feed himself, he can put in his own hearing aid, his glasses, and he can wash his own face and hands and more or less the front of him. He doesn’t have the balance to do things like shoes and pants.

Most of the time now he works at his desk, and he’s always got a radio or some music on. We do sweepstakes together sometimes. We love the thrill of sweeps. We both enjoy the same type of music; we both enjoy watching the birds. I did sweepstakes before I went to Kevin’s. I enjoyed the birds before I went to Kevin’s and music is something I’ve always loved. Those were three hobbies that I came along with and that we could communicate with when I started working with Kevin, and we share these things even after eleven years. I’ll also do things like helping him file receipts and credit card bills. I let him do just as much as he possibly can. The one thing I learned was give people just as much control as they can with their own lives. When you start taking control by over-helping

them, you’re not doing them a favor. They’re going to resent it.

There is a certain understanding and insight Arlene has into Kevin’s needs that could never form between people who only share a few hours a week for a short period of time. Arlene knows Kevin as a person and as a friend.

Understanding Kevin is one of our biggest problems. He has had trouble talking since I started to work for him; it’s part of the MS. Of course, the more people try to get him to talk the more tired he gets, the weaker his voice gets, the more frustrated he gets. And when he gets frustrated he’ll take a deep breath and he’ll yell because that’s how he can make them understand. A lot of them think he’s being mean. *He’s not.* He’s trying to do it the only way he can do it.

I’ve tried to explain it to the other caregivers, but there are times when I just have to say, “Hey, don’t get upset. Yes, he’s frustrated when he yells. But you need to understand he’s frustrated because he can’t talk the way he wants to talk.” With younger people, they automatically think he’s mad at them. He’s not mad; he’s frustrated.

Say Kevin’s in the other room and he wants something. He might say, “Arlene I dropped my pencil.” I’m not going to hear what he said. Nobody’s going to hear what he said because he’s got the TV going, he’s got the radio going, or I’ve got the washing machine running or something. I hear “Arlene,” but I’m not going to hear what else he said. So I drop what I’m doing, go into the room and say, “Kevin, I didn’t understand what you said. What was it?” I get right in his face directly, he repeats it, and I get it. I do what he wants done; I go back to doing what I was doing. It’s so simple to me, I don’t see where there has to be a problem.

The new girls are the ones that pay hell because they’re the ones that aren’t used to the routine. They’re the ones that ask him questions and wear down his voice so they have a hard time understanding him. Some of them do better than others. And some of them will come in and say, “Well, I’ll do this for you, you don’t need to do this yourself.” Or some will say, “He needs to be in a nursing home. He’s too much care to be here.” I’ve come right out and said, “There’s nothing wrong with his mind. His kids do *not* need to put him anywhere and you do *not* need to talk down to him. You need to show a little bit of compassion.”

(cont’d on back)

The future is uncertain for Arlene and Kevin at this point. Medicare, which is the source of the funding that pays caregivers who work in Consumer Directed Programs, is being cut. The programs at the state level which govern it are being shifted from one department to another as the state of Maine struggles to manage skyrocketing healthcare costs. Changes happening on the legislative level are affecting people like Kevin and Arlene in a very real way.

Insurance and paychecks are problems that we've been dealing with forever, but the biggest thing we're dealing with right now are all these cuts in funding through Medicare and MaineCare cuts to the agencies that do the Consumer Directed Personal Assistance Services Programs. One effect of all of these cuts is that we expect to lose hours of care for Kevin. More than likely I feel that Kevin will end up in a nursing home - if not right after his care gets cut back, very soon thereafter. He just is getting worse and by getting worse he needs more care, not less. He's been lucky to stay home as long as he has. But, we can only volunteer so many hours. We've got families. And basically that's what it boils down to is if he needs the help and we can't get paid for it, we're going to be volunteering.

If he doesn't have me and the other girls who've been around forever to care for him anymore, the state's going to have to

start paying for physical therapy. They're going to start paying occupational therapy for him. Right now I and his other caregivers have a say in his therapy because we've been around him so long. We just look at him getting around and say, "Kevin you're doing it this way. How about if we do it that way?" We know how he moves. Somebody else as an occupational therapist has to come in and watch him, and see him do something several times before they get the body mechanics of how he moves. It's going to be completely different in a nursing home setting. They won't know him.

Thinking about losing Kevin to a nursing home is hard, because I get a lot of satisfaction knowing that I'm helping somebody in the final stages of their life. While they're here I can do the best I can do to make their lives more comfortable. And that's the same thing I want for me when my time comes. If tomorrow I'm going to be in a wheelchair for the rest of my life I want somebody with some compassion, somebody that can laugh with me, somebody that can cry with me, and somebody that makes me feel comfortable to be around - and that I'm not a burden.

**The names in this story have been changed.*

What Are Consumer Directed Services?

When a person with a disability (a consumer) employs their personal assistant/attendant or direct caregiver rather than arranging the employment through an agency, they are participating in a Consumer Directed Personal Assistance Service (CD-PAS). In CD-PAS the consumer is responsible for hiring, supervising, training, paying and firing the personal assistant/employee. Payment for services is covered: by the consumer from their own funds, by the consumer through private funding, or through participation in federal or state Medicaid programs that allow eligible consumers to utilize these funds for home and community-based living to support their independence.

Why are Consumer Directed Services so important?

Consumer Direction give consumers maximum control over their support services. The benefits of the CD-PAS for the consumer include independence and more flexibility with their services, the ability to hire providers that they feel will do the best job, and the ability to pay family members or friends who provide assistance. The benefits for workers include working with just one or two consumers for a longer time each week. This encourages direct interactions and familiarity and communication to develop between caregivers and consumers that enable longer lasting work relationships. The scheduling is more flexible since providers aren't following agency time guidelines, and there is more of a sense of control since a provider is not accountable to an agency, but rather to the consumer. Some of the drawbacks include lack of benefits like paid leave, health insurance and overtime.

How is CD-PAS employment supported?

The Personal Assistant's pay may come from Medicaid reimbursement paid to the consumer for services they receive based on eligibility for participation in the state or federal programs. Independent Living agencies like Alpha One of South Portland and

Bangor provide assistance to eligible consumers who are organizing their own programs and directing their providers. They also provide some education, training and equipment.

Who is eligible for CD-PAS Programs and Services?

The standards people have to meet to qualify for Medicaid-funded CD-PAS are determined by the State. All participating consumers must meet the income guidelines defined by Medicaid. Elders 65 and older must meet the state standards for eligibility for a nursing facility. Those 64 and under must meet the state's definition of disabled. (Explanations of these standards are available from the Maine Department of Health & Human Services. Their contact information is listed below.) Support providers can be any family member (except the consumer's spouse or parent of a minor child), friends or community members, or people who apply for the job and are hired by the consumer. The State doesn't require providers to have formal training though some consumers do. Some services, such as physical therapy and management of medications may have to be provided by trained individuals.

Where do you get information about CD-PAS Programs and Services?

- **Alpha One Center for Independent Living**
voice: (800) 640-7200, TTY: (866) 906-5375
- **Maine Department of Labor
Bureau of Rehabilitation Services**
voice: (800) 698-4440, TTY: (888) 755-0023
- **Maine Department of Human Services
Bureau of Elder and Adult Services**
voice: (800) 262-2232, TTY (888) 720-1925