



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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Maine PASA Representatives Present in Baltimore



Roberta Record, PCA with Bridges Home Care, and Julie Moulton, DSP with Support Solutions, represented Maine PASA and were a voice for direct care and support workers at a national conference.

Direct-care workers were on the agenda of the third annual Real Choices Systems Change Conference hosted by the Centers for Medicare & Medicaid Services (CMS). Roberta Record and Julie Moulton addressed an audience of 150 attendees on March 1st, participated in the main conference, and hosted a poster session.

The March 1st audience was a mix of state policymakers, researchers, consumers, worker advocates, and agencies that coordinate personal assistance services who are working to improve access to home- and community-based long-term care services with the help of CMS grant money. They heard from the workers about why they had chosen their profession, why they stay in it, why they thought others left, and what could be done to make the job better.

Moulton talked about the need to increase respect for direct-care workers. "I shared that I am still referred to, at times, as a babysitter," she said in an email exchange with Quality Jobs/Quality Care. "We have a huge PR job in front of us. I think we all want to be recognized and respected for the importance of the work we do."

Record says she talked about liking her job because "there are no bullies," she isn't confined to "looking at a computer all day in a windowless room," and she can "use [her] creativity." As to why others leave the profession, she says: "I told them, 'This is tax time, and my W-2 just told me that that I made \$9,965 last year.' One gentleman came up to me afterward and said, 'Even if you had health insurance coverage available you wouldn't be able to afford the co-pays, would you?' I said, 'That's right.'"

"People seemed to be in agreement: this was not, for the most part, news to them, but hopefully hearing it firsthand [from direct-care workers] helped them to understand," says Moulton. "I had several people approach me to thank me for sharing. It was wonderful to know I was heard. It was also heartening to hear what the attendees were doing to improve conditions for direct-care workers and long-term care recipients. I was astounded by the amount of projects that are underway, sponsored by the grants. I returned home with new enthusiasm, knowing that so many creative ideas were being tested. I am excited to be able to return to my home state and share some of these things, and the hope that goes with them."

Attending the conference "really helped me to see the bigger picture and what's going on," Record agrees. "It also gave me an opportunity to talk about elder issues."

To read the full article:

<http://www.directcareclearinghouse.org/news.jsp#0431101>

Upcoming Maine PASA Meetings

Meetings include a topic of interest and a Maine PASA update.

Portland: June 9th, 4:30p-6:30p

Topic: Life Stories, the Value of Knowing Your Consumer/Client/Patient
University of Southern Maine Campus Center

Brewer: June 19th, 4:30p-6:30p

Topic: Life Stories, the Value of Knowing Your Consumer/Client/Patient
OHI Training Center, Oak Room

Augusta: June 23rd, 4:30p-6:30p

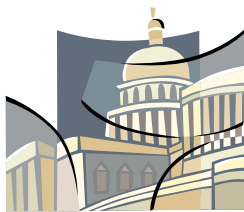
Topic: Working with High Physical Needs Consumers
University of Maine-Augusta
Women, Work & Community Conference Room

Members and interested guests invited!

For more meeting info and directions, call Maine PASA (voice: 800-268-6612, TTY: 800-809-4501) or visit www.maine-pasa.org.

Maine Updates

Legislature recognizes DSPs: HP 1460, a joint resolution sponsored by Rep. Margaret Craven, unanimously passed in recognition and support of Maine's Direct Support Professionals. The vote follows a national initiative by ANCOR, the American Network of Community Options & Resources. (Visit ANCOR at ww.supportnac.org)



LD 1753 passes: Agencies in Maine are prohibited from hiring unlicensed assistive personnel (PCAs) with criminal backgrounds. This extends the rules currently followed for CNAs. Plans for a PCA registry are being discussed.

LD 1090 Resolve is expanded: The Legislature did not agree to raise Medicaid reimbursement rates to fund wage and benefit increases for direct health care workers but they endorsed the work of Maine's Direct Care Worker Coalition and the need to monitor workforce shortages, wages and benefits, including personal assistants working in consumer-directed employment. The next public hearing is January 15, 2005.

DHS/BDS Merger: The act to merge the two departments was passed in LD 1913 and will be phased in. The final report is available on the state website: <http://www.maine.gov>. Select Government and News to do a search for Unification report.

Dirigo Health introduces CareWorks: The Dirigo Health Act enacted in 2003 to initiate programs for cost containment, quality improvement and affordable insurance coverage is expected to be offered to eligible small businesses this summer. An outline of the proposed insurance plan, CareWorks, was presented by the Dirigo Board and the Governor in a press conference on March 25th. A summary of the plan is available at www.dirigohealth.maine.gov.

State Budget: The Legislature continues to work on the 2005 budget. A final vote is scheduled for April 30th. Cuts in Medicaid funded services are expected but the extent of the cuts and who they will impact has not been finalized. Maine PASA had a representative at the March 15th public hearings on proposed Medicaid cuts. Julie Moulton reported: "Many powerful stories were told by consumers and providers about the cost of the cuts and how losing these services is not fiscally sound, as well as personally devastating, as they would, in effect, lose their independence, become disabled and require much more in terms of direct care services. Concerns were voiced that the impact would effectively increase the need for direct support assistants when there is already a shortage."

ME JAC Update by Roberta Record, PCA, Worker voice on the Council: The Maine Joint Advisory Council is concerned about program changes that will effect the Alzheimer's, dementia, disabilities, and mental health community. MEJAC plans to inform and educate legislators about Alzheimer's and dementia and the risks in Maine. The National Public Policy Office of the Alzheimer's Association wants to work with Maine's Challenging Behavior Study work group to implement a new mandatory training for nursing homes on dementia with a focus on challenging behaviors.

Grant Update - Recruitment and Retention Projects: The cost of recruiting, hiring, training and retaining a quality workforce is a concern for employers and is the focus of committee and grant projects statewide: *Direct Care Worker Coalition* initiated LD 1090 and is discussing education, training and wages/benefits. *Maine PASA* was developed through the Real Choices grant and *The Workforce/Dirigo Grant, Providing Health Coverage and Other Services to Recruit and Retain Direct Service Community Workers in Maine: The Dirigo Difference* was awarded to the Governor's Office of Health Policy & Finance to address the need for health care benefits and employer-based support for the recruitment and retention of home and community-based workers. For more information, contact Elise Scala at (voice) 228-8423 or (email) scala@usm.maine.edu.

Introducing Our Board of Directors

Maine PASA has come a long way. When the idea of an association for people employed in direct care, direct support and personal assistant work was announced in October 2002, we were part of a new grant project in Maine. Now, we are a growing, active group that has statewide members and goals. In order to serve the members well and accomplish these goals, we need to be organized in a way that will guide us to operate effectively and be recognized by the State and other groups. The dedicated group of workers and grant staff that started Maine PASA is taking the steps needed to become a non-profit corporation. The newsletter will keep you informed of our progress. If you have any questions, please contact us. (See back of newsletter for contact info.)

Maine PASA has asked a group of its members and supporters to lead this process, and it is with great enthusiasm and appreciation that we introduce our Board of Directors.

Interim Board Officers: Chairs: Julie Moulton, DSP, and Susan Tucker, PCA, CNA; Vice-Chair: Trish Richard, DSP; Treasurer: Mike Payne, CFO, Home Resources of Maine, Inc.; Secretary: Gail Benvenuta, facilitator, project coordinator and experienced board member

Board Members: Sherrie Bergman, experienced caregiver, administrator, and board member; Ginny Carroll, Bureau of Employment Services, Maine DOL; Jennifer Gillespie, National Academy for State Health Policy; Kim B. Hale, experienced caregiver for elders and people with disabilities; Susan Levandoski, RN, Mid Coast Senior Services; Roberta Record, PCA working with elders, thinker and writer

Advisory Member: Pam Studwell, Esquire, Legal Services for the Elderly

Board Staff Assistants: Rachel Dyer and Elise Scala



Congratulations, Olga!

Katherine Gross was born on April 24th at 3 a.m. She weighed in at 7 lbs., 10 oz. Everybody's doing great!

“Get Acquainted with Maine PASA” Gatherings Are in Gear Around the State

by Gail Benvenuta, Maine PASA Membership Development Coordinator

In March, Maine PASA invited PCAs, CNAs, DSPs, PSSs, PAs, advocates, consumers and agency administrators to learn about and discuss the Association. These meetings also proposed priority areas to be addressed in our upcoming regional meetings.

The gatherings started off by introducing Maine PASA's Oral History project, with writer/historian/Maine PASA member Jocelyn Barrett. Attendees introduced themselves and told about their caregiving and personal assistance work. The introductions gave rise to lively and stimulating discussion about work in caregiving and personal assistance.

Maine PASA founding members presented the group's accomplishments of the last year and a half. Membership and activities are growing! (Check our website to see how Maine PASA has developed: www.maine-pasa.org.) While the conversations were a little different in each meeting, our discussions raised common themes. We used these themes to develop topics for upcoming meetings. (See page 1 for upcoming meeting dates.)

Logistics:

- Portland and Augusta meetings will alternate between Saturday mornings and a Tuesday/Thursday night.
- Bangor area meetings will be held Saturday mornings.
- Planning is beginning for June meetings. (Not to conflict with schools ending and summers beginning!)

Activities/Topics:

Each group brainstormed topics and ideas around “What will motivate us to gather?” So many “needs” and “wants” were named that we can plan activities for the next three years with no problem! We have a rich well to draw from as the Association grows! Following are suggestions that were made by attendees for upcoming meeting topics:

- Legislative issues/updates
- Invite policy makers to come to Maine PASA meetings
- What are the workforce issues?
- “Best Friends” training
- Hospice training for ourselves (*i.e.*, addressing issues of loss and grieving for direct care providers)
- Networking with other direct care workers, learning about the range of services, kinds of positions, and what goes on in other agencies
- Resource sharing (for our own training, as well)
- Learning about what's out there for workers and consumers (*i.e.*, a “Directory of Services”)
- Training (*i.e.*, First Aid, CPR, Wellness)
- Boundaries and discussion about employer/State policy
- Issues of isolation

- Issues of team and teamwork
- Working with a high physical need consumer
- Safety issues in the home (*e.g.*, chemicals)
- Burnout
- New workers (*i.e.*, supporting them through peer mentor programs)
- Mental health issues (*i.e.*, working with people with MI)
- Empowerment tools
- Building hope



Don't forget to check out the Maine PASA website!!

www.MainePASA.org

Our features include:

Our Stories

What are other direct care workers doing?
Find out by reading one of their stories!

Upcoming Events

Go here for a listing of regional and national events.

Newsletter Archives

Find every newsletter we've ever published!

Resources

A great page for links to sites and articles that you might find handy.

Is there something you want to see on YOUR website?

Let us know by clicking on the Contact Us link!

Books To Share

Do Unto Others: Extraordinary Acts of Ordinary People

by Samuel P. Oliner (ISBN: 0813339847)

A passing motorist stops to help the passengers of a car that has crashed into an embankment. A hospice volunteer begins her shift in hospital ward caring for people with AIDS. A Vietnam chopper pilot stops the brutal execution of innocent civilians at Mylai by American soldiers. A firefighter responds to a routine call. All of these people are considered heroes, but what motivates such brave and altruistic acts, whether by trained professionals or just ordinary people?

The Blue Day Book

by B. Trevor (ISBN: 0740704818)

A wonderful collection of amusing, poignant animal photos and inspirational text designed to lift the spirits of anyone who gets the blues.

Courage of Conviction: Women's Words, Women's Wisdom

by Linda A. M. Perry and Patricia Geist (Eds.) (ISBN: 1559347163)

This anthology contains twenty concise, original essays profiling women who have found "voice" and overcome the forces that historically have restricted, ostracized, and silenced their voices.

The selections examine their personal and social obstacles as well as their accomplishments and empowerment through works, words, and actions.

Do it Anyway

by K. Keith (ISBN: 1930722214)

The handbook for finding personal meaning and deep happiness in a crazy world.



You're Invited to Join Us!

Are you a CNA, PCA, HHA, DSP or PSS? Do you provide direct support or care for an elder or a person with a disability? Contact us for more information!

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Excerpts from “Warmth and Wisdom: Roberta Record’s Story”

by Jocelyn Barrett, writer, historian, Maine PASA member

Roberta’s story is the first in Maine PASA’s “Our Stories” series, highlighting the experience of Maine caregivers. **This edition is an excerpt prepared for the Maine PASA Newsletter. The complete version can be read on the website, www.maine-pasa.org by clicking on the Our Stories page.** The stories are told in their own voices. These stories are about what Maine caregivers, support professionals, and personal assistants have seen with their eyes and felt with their hands and hearts. Much of the value of direct service workers is simply that they preserve human dignity, and they make people’s lives better through the difficult, often undervalued work they do. The “Our Stories” project can only provide snapshots of the work they do every day, we hope it will help us all to see how vital and amazing this work - and the people who do it - truly are.

Roberta Record is a dedicated PCA who lives and works in the Augusta area. Her caregiving experience with elders began when she took over her mother’s business in the early 1990s, which provided in-home support and care to elders in the community. “At that time,” Roberta says, “families would pay people in the neighborhood to help them. I don’t know how long the agencies have been in existence that are providing homecare, but this was word of mouth – who you could network with.”

After working for a homecare agency for six years, Roberta faces the challenges and triumphs of her day-to-day experiences with a creative and loving spirit. She is committed to lifelong learning, and is active in many groups. She is an avid reader and creates collages and paintings that cover the walls of her modest, comfortable apartment. Some of her collages tell the stories of elders she has cared for and learned from in her time as a PCA. The wisdom Roberta has gained from her caregiving experience shines through when she tells a story about an elder that was dear to her. Roberta is a storyteller, whether she’s writing, making collages, or talking about her work, what she gives to those around her is colorful and rich.

Learning Something New All of the Time

In the latter part of 1995, one of my male friends was dealing with his mom who needed 24-hour care. She was 93, and she was only going to live thirteen days. A home health nurse had predicted when this woman was going to die. At the time, I didn’t have any opinions about that, but I’ve developed them now. Nobody has the right to say how long somebody is going to live. In my job, elders will say to me, “Am I going to live or die?” And I say, “It’s up to you. If you don’t want to eat, then you can count on dying. If you want to live a little while longer, you need to drink your Ensure.”

So I was hired to go over and spend time with this woman, Lena. I would come in with these little projects because I figured that I needed to entertain myself from the boredom of doing nothing. Well, evidently she caught on, because she started having the time of her life. I would go over and bring her newspaper to her, tell her what was going on in the community. I started reading poetry to her. She was only supposed to live thirteen days. That thirteenth day things were kind of heavy. I walked into her house and I said, “She’s supposed to die today.” Well, it turns out I was with her from January to November. It was like maybe God wanted me to spend some time with her – more than thirteen days – before she passed on.

Shifting Roles

There’s a transition happening from families taking care of elders to strangers taking care of elders. I experienced that when I started working for the agency. I was assigned cases. The worries for both myself and the consumers are: How are they going to treat me? Are my possessions going to be stolen? Is money going to be stolen? My elders and I build a relationship. The first day I’m there I say, “Did you enjoy the visit? Did you feel comfortable with me? If you don’t, then we can find another caregiver because this is important. We’re going to be spending a lot of time together.”

If it doesn’t feel comfortable, I’ll let the agency know. They are very responsive to me because it’s good business. I hate to say the word “business,” but it is a business. Maybe three or four years ago it was required by the state to have PCA training, and now to work for

an agency you have to have your certificate. But basically the stuff that I do is common sense, though it seems like I often have to allow other's decisions to override mine. That is totally against my whole philosophy of life. To be a part of the decision process, to be taken seriously, is the value of a caregiver. And yet, I can understand why I have to always "run it by somebody." If something goes wrong, there are plenty of people who will point the finger.

Breaking a Frozen Thought

It's amazing how you can break a frozen thought. Like, some people will say, "I don't like poetry." I'm thinking of one lady that I went to in Wiscasset. She lived in a trailer. Now, I go from extremes in terms of economics. That is one of the most challenging experiences, to go from someone who has a savings of \$400,000 to someone who's living in a trailer who has nothing. In fact her daughter left her job as a cook in Rangeley to come down to Wiscasset and care for her father, who died of cancer. Her mother had nine strokes, was a diabetic. This daughter had left her income so she could live in a trailer and care for her mother. You know, there are so many kind, caring, gracious people that have a spiritual richness that a lot of wealthy people don't have. I find that profound. On this day, the daughter was telling me that it took her six hours to feed her mother three meals. She would have to stroke her mother's throat every time she gave her something to eat because the throat muscles were partly paralyzed.

I was only there for a day with them. Her daughter and I literally had to roll her in a secretarial chair into her little tiny bathroom that had the washer and dryer in it, and the two of us lowered her down into the bathtub that was padded with air pillows. I was to take forty-five minutes and pour warm water over her body. Well, I was having a difficult time doing it because she was so thin and stiff. And the muse was telling me, "Rigor mortis is setting in, but I'm alive. I'm alive." So I thought, I've got to go out to my car. I happened to pack Robert Frost. I said, "I'm going to read you the poem, 'The Pasture,' and if you don't like that poem, I'm going to stop." So after I read 'The Pasture,' I said, "You want me to read another one?" She said yes. So, sitting in the secretarial chair I poured water over her body as I read Robert Frost. Her eyes were closed; it was too much energy to keep her eyes open. And I

would say, "Do you want to hear that again? That's such a great poem." And she would nod yes. I spent forty-five minutes reading Robert Frost to her. And then we very carefully lifted her up and wrapped her up and put her on the chair and rolled her back into her bedroom. I had to put lotion on her and I was not trained for that, not at all. It was very shocking.

I was supposed to be there once a week as a respite person. The following weekend I had these – I don't know – intuitions, feelings. I just couldn't get her out of my mind. I relived that visit over and over again. And the next day I called the office to let them know that I had been sick with the flu and I didn't want to contaminate this woman. And the staff person said, "Oh, Roberta, didn't you know? She passed away this weekend." Well, I thought to myself, "In the short time I spent with her, I was walking her into heaven."

Jocelyn Barrett will be working with Maine PASA members to complete a project for her Bachelor's degree. She will also contribute to the Maine PASA website and newsletter. Jocelyn has worked as a Dietary Aid and PCA while in school, and has the insights of growing up in a household supported by her mother's works as a CNA and home health caregiver. She is using the Feminist Oral History model, which uses a spoken story or conversation as the basis for the written story.

You may contact her by calling Maine PASA (voice: 800-268-6612 or TTY: 800-809-4501) or by emailing her at jocelynbarrett@hotmail.com.

