

The Illustrated History of Maine PASA:

Establishing an Association for Direct Care and Direct Support Workers in Maine



*A Grant-funded Project to Start the
Maine Personal Assistance Services Association*

This report was prepared under a Cooperative Agreement between Muskie School of Public Service and Maine Department of Health and Human Services with funding from the federal Centers for Medicare & Medicaid Services.

UNIVERSITY OF SOUTHERN MAINE

Muskie School of Public Service

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This report was produced as part of the development of the Maine Personal Assistance Services Association (Maine PASA). Maine PASA currently oversees the Our Stories series.

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Presented as part one of a two-part report on the development of a worker association

“An association is where you can have your voices heard and people will listen.”

—direct care worker attending the kick-off meeting

A grant-funded project to start the Maine Personal Assistance Services Association



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Terms like building, developing, recognition, capacity building, empowering and growing opportunities were listed on flip charts for crafting the Maine PASA mission statement.

Introduction

The history of Maine PASA, how it started and grew, is illustrated in this report as a timeline of activities, challenges and outcomes. Rather than describe the development of Maine PASA as a sequence of events that started in 2001 with a grant award and transitioned to a non-profit organization in 2005, it is far more accurate, and informative, to illustrate the developments with examples and pictures of its productivity. From the day the funds were granted this project was a venture that grew to become a statewide association. We looked for a metaphor to describe the process, experience and multiple factors that influenced the development of Maine PASA. Some called our work grass-roots organizing, others called it cultivating capacity. The grant staff described themselves as boat builders, and the end of the grant was to be the day the ship set sail. Many said it was about time that workers were recognized. Some voiced suspicion that it was union organizing. A few said it was unnecessary. Many who became members told us stories of caregiving, nurturing and consumer dignity. Terms like building, developing, recognition, capacity building, empowering and growing opportunities were listed on flip charts for crafting the Maine PASA mission statement. One of the founding members, Trish Porter, introduced herself as a Life Skills Coach at the first grant-funded event to launch the concept of an ‘association’ for direct care and direct support workers in Maine. Trish was one of a handful of people who quickly identified with the potential of an association. In recognition of Trish and the other founding members, Olga Gross, Kim Hale, Julie Moulton, Diane Nadeau, Roberta Record, and Susan Tucker, the metaphor selected to describe Maine PASA is the sprouting seed held in a pair of caring hands. A print of this picture was given to Elise Scala, the grant project coordinator at Maine PASA’s first official conference in 2003. The illustrated history of Maine PASA describes the stages of development from a seed to a productive, blooming and rooted organization. Within the timeline of growth the story is also a report to our funders of grant activities and outcomes, lessons learned, expected and unexpected challenges, and the ambitions for long-term outcomes and sustainability.

Over the four year grant period 2001-2005 (three grant years plus a one year no-cost extension) the project went from an idea to address the workforce shortages by building a worker-centered organization to a nationally recognized incorporated non-profit 501(c)(3) worker association with statewide membership of over 600. This germination and growth is illustrated in this report, describing the activities, events, challenges, decisions and people that are the history of Maine PASA. This is one of two reports about Maine PASA produced following the completion of Maine’s Real Choices Systems Change grant, awarded by the federal Centers for Medicare & Medicaid Services. The second report, Our Stories Project, is an oral history of the workers and their work.

The role of personal assistance workers was identified as a critical support service in every aspect of independent living, and the challenges in recruiting and retaining people in this work were a major concern.



Background

The 2001 federal Centers for Medicare & Medicaid Services (CMS) Real Choices Systems Change Grant established a focus on the direct care and direct support workforce and marked an important starting point in Maine. The goals of the grant were based on the comprehensive review conducted by Maine's Work Group for Community-Based Living to develop the State's *Olmstead* plan. Key findings from focus groups identified weak links in the system of services and support either because they were inconsistently available, or inaccessible to people with disabilities.¹ The role of personal assistance workers was identified as a critical support service in every aspect of independent living, and the challenges in recruiting and retaining people in this work were a major concern.²

This finding was reported in the Work Group's report:

Problem Area #3: Improving access and availability of key supports identified the need to "expand the availability of frontline workers" since the workforce shortage threatens home and community living options.

The Real Choices grant was a timely opportunity to demonstrate the interventions needed to address these findings. (See Appendix 1.) The three-year grant proposed the following goal and plan for Project Activity c-3:

- a. **Project Goals:** To support the development of a Personal Assistance Worker Guild to increase the availability of qualified personal with a deliverable for a sustainable, independent Guild that will provide benefits, support, continuing education and advocacy for its members.
- b. **Implementation plan:** To utilize grant funds to stimulate the formation of a worker-directed organization through an RFP process to a community organization. The grant staff will conduct literature reviews to develop the guild model and implement its development through a contractor.

The activities and outcomes accomplished over the four-year grant period were completed through partnerships. Support for Maine PASA grew from a common concern about the availability and quality of the workforce, and the quality of the jobs to deliver services to Maine's elders and citizens with disabilities. The grant cultivated and supported Maine PASA to become self-governing and operational as a non-profit organization. In 2005, in closing the grant, Maine PASA represents itself and its members in numerous activities to extend the goals of the grant into the future.

¹Work Group for Community-Based Living. (October 2003) Roadmap for change: Maine's response to the *Olmstead* decision. University of Southern Maine, Muskie School of Public Service: Portland, ME.

²Bratesman, S. (December 28, 2000) Direct care workforce challenges: Improving the recruitment and retention of workers who provide direct support to persons with disabilities. University of Southern Maine, Muskie School of Public Service: Portland, ME.

Maine PASA Activity Timeline



October 1, 2001

CMS Real Choices Systems Change grant awarded.



October 2001 - March 2002

Conducted literature review and formed national contacts.



October 26, 2002

"Breakfast for Personal Assistants and Direct Care Workers," Lewiston-Auburn College, Lewiston, ME, Association introduced.



November 2002

Maine PASA formed by grant staff and core group of workers. Newsletter launched.



February 4 - April 2, 2003

Maine PASA members work with the Direct Care Worker Coalition to present legislation to address low wages and benefits.



March 2003

Maine PASA mission statement drafted and logo developed.



April 2003

Maine PASA begins facilitating a monthly telephone conference of other state-based associations. New England Coalition of Worker Associations and Advocates begins to meet.



May 2003

Founding members present Maine PASA at Health Care Job Fair, South Portland, ME.



September 2003

Maine PASA representative invited to join Maine Joint Advisory Council (MEJAC), Augusta, ME.



What could an Association do for workers in Maine?

What the workers said.

An association will . . .

- Empower us to preserve human dignity.
- Help us address issues like continuity of care and short staffing.
- Give affirmation.
- Help us make changes.
- Provide camaraderie.
- Other people would view us as professionals.
- Other people would see us as valuable.
- Other people would see the people we serve as valuable, including older people, people with disabilities, both children and adults.
- Our voices could be solidified (and unified) and people would listen.
- What would we tell people? Pay us what we're worth. Treat us better in other ways also — give us more positive feedback.

(Continued "why" Side 2)





October 3, 2003

Maine awarded CMS Direct Services Worker Demonstration grant to engage workers and build communications resources and the organization.



October 16, 2003

Maine PASA introduces Maine PASA to 16th Annual Direct Support Professionals Conferences: "Communications and Community Connections," Bangor, ME.



October 26-28, 2003

Maine PASA presents at National State Units on Aging, National Home and Community-Based Waiver Conference, Milwaukee, WI.



November 2003

www.MainePASA.org launched.



November 14, 2003

2nd Annual Maine PASA Conference: "Building Our Capacity and Valuing Our Work," Lewiston-Auburn College, Lewiston, ME.



January 2004

Maine PASA forms a Board of Directors.



February 2004

Our Stories project launched.



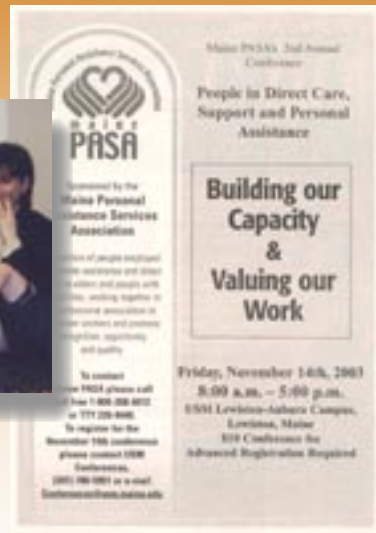
March 2-3, 2004

Maine PASA members present and hold poster session at CMS Project Directors Conference.



March 27, 2004

Brewer Chapter introductory meeting held.



Portrait of Julie Moulton

Julie Moulton works as a direct support professional for a resident care agency in Winthrop, Maine. In her role as a direct support professional, Julie provides personal support to adults with mental retardation and development disabilities. We asked Julie to describe some of the challenges associated with her job.



Maine PASA Activity Timeline



May 4, 2004

Maine PASA Board of Directors holds its first retreat.



July 2004

Maine PASA applies for business status with the state.



August 2004

Maine PASA Connections Advisory Board convened to get input from consumers and workers.



September 2004

Maine PASA representative asked to serve on the Legislative Task Force CD-PAS Work Group, Augusta, ME.



September 17-20, 2004

Maine PASA members present at Direct Care Alliance National Conference and visit Congressional and Senate offices., Washington, DC.



September 27, 2004

3rd Annual Maine PASA Conference: "Excellence in Long-Term Care," Augusta, ME, Co-sponsored with Maine Long-Term Care Ombudsman Program, Maine Healthcare Association, First Atlantic Healthcare and Maine Home Care Alliance.



November 2004

Maine PASA incorporated and registered with the state.



December 2004

Maine PASA conducts competitive search for an Executive Director.



December 2004

Maine PASA surveys its members to get input on newsletter, website, and chapter development.



Job Fair Preview Session

Members of Maine PASA were well represented at the Health Care Job Fair in South Portland on May 19th. The brochures and sign up sheets, boosted by the enthusiasm of member outreach successfully informed many Fair attendees and recruited over thirty new members!





December 2004

Maine PASA Connections, www.MainePASA.org/Connections, goes live.



January 2005

Maine PASA granted 501(c)(3) status.



January 2005

Maine PASA hires Roy Gedat to be the part-time Executive Director.



January 2005

Maine Alzheimer's Project awards contract to Maine PASA to fund member attendance to Best Friends™ Approach to Alzheimer's Care training programs.



June 2005

Maine PASA becomes a member of the Home Care Alliance of Maine and of the Developmental Disabilities Council.



July 2005

Maine PASA Board of Directors members complete first-term. Nominations for new members announced.



September 2005

Maine PASA has an active statewide membership of 620+.



For an annotated listing of Maine PASA activities (2001-2005), see Appendix 14.

Announcing the Maine PASA website!!

*Currently under construction!
Coming to a computer near you!*

www.MainePASA.org

SPECIAL REPORT

Without Care: Maine's Direct Care Worker Shortage

Maine Center for Economic Policy, Author Lisa Pohlmann



Maine Direct Care Worker Coalition: Coordinates State Efforts to Address Worker Shortages

A subcommittee of the Coalition has initiated a bill to the Maine Legislature to increase wages for Direct Healthcare Workers in Maine.

pay/benefits and this increasing worker shortage.

They are saying what we as direct care workers have known for years. Now it's at a critical

problem of low wages, limited benefits and long hours. A bill will be introduced to ask the legislature to increase wages and benefits. Hopefully the





It was evident within the first few months of the grant that both the terms in our project goals and the direct care workforce in Maine would influence how the project would proceed.

³Stone, R. (Spring 2001) Research on frontline workers in long-term care. *Generations* 25(1) 49-57.

⁴Stone, R. and Wiener, J. M. (October 2001) Who will care for us? Addressing the long-term care workforce crisis. *The Urban Institute: Washington, DC.* and Stone, R., Dawson, S. L. and Harahan, M. (October 2003) Why workforce development should be part of the long-term care quality debate. *Institute for the Future of Aging Services: Washington, DC.*

Testing the Soil: The Start-Up Work

Questions and Decisions:

- What's the climate in Maine?
- What is a guild? What is an association?
- Is there a worker-directed organization in Maine for these workers?
- What models exist in other states?

■ What's the climate in Maine?

While other states, like Iowa and Arizona, had active organizations for direct care workers, the concept was relatively new in Maine. The Iowa Caregivers Association served as a model for grant staff and the Executive Director Di Findley was very familiar with our purpose, and challenges. Literature on the 'care gap', the difference between the rising demand for direct care workers and the shrinking number of women ages 24-54 to fill the jobs, was beginning to appear in national publications.³ Robyn Stone and other researchers in long term care were writing about the challenges in recruiting and retaining workers in direct healthcare and the impact on the quality of care. While many regional and national experts were focusing on the shortage of RNs and other health care professionals the focus on the 'paraprofessional', direct care level staff was relatively new.⁴ The growing amount of literature and the news that some states, like Massachusetts were declaring their workforce shortage to be a crisis warranting expansive legislation provided terrific resources for explaining our work in Maine . . . to a point.

There were some unique aspects to our project that were important determinants for the start up activities. It was evident within the first few months of the grant that both the terms in our project goals and the direct care workforce in Maine would influence how the project would proceed. First, our proposal referred to the group to be developed as a 'Personal Assistance Worker Guild'. This raised interesting questions about the title of the workers to be targeted, and what a 'guild' would look like. The contacts made by the grant staff over the first year provided a wealth of information for understanding the terms for workers and worker organizations. It was very helpful that two other states awarded Real Choices grants, North Carolina and Vermont, also had initiatives to start paraprofessional worker organizations, and that the Maine grant had established a Technical Advisory Groups to serve as advisors and resources to our projects. (See Appendix 2.)

Having the background information from other model programs and some key support people in the state was extremely helpful but did not readily identify how a workers' guild would develop in Maine. While the project was gaining an audience it was not immediately apparent that people

supported the concept, and limited data was available about the workforce in Maine.⁵ Contacts with providers and consumers and the employers of direct care workers were very informative. It was very striking that many providers identified our goals with the work of union organizers. This presented challenges that continue to have an impact on Maine PASA. While few health care and long term care facilities in Maine have collective bargaining for nursing staff it was very clear that organizations were/are seriously opposed to organized labor. They could however voice their appreciation of the fact that wage rates for direct care and personal assistance staff at the aide and homemaker levels were low and that benefits like health insurance were either not available or unaffordable. A common theme heard by grant staff was that Medicaid reimbursement rates, a primary funding source for many providers, did not adequately cover operations costs and therefore provided no margin for wage increases or benefits for direct care staff. Examination of the staffing across the Medicaid providers revealed a diverse array of workers at the entry, direct care and assistance level employed in a number of sectors; hospitals, nursing homes, home health care, adult day services, and home-based consumer directed programs. The evidence was mounting that there were a lot of job titles for this group of workers, they employed thousands of people in all long term care sectors, the general public knew very little about what they do, and the concept of a worker association was unfamiliar to many. And when you said ‘guild’ everyone assumed ‘union’.

Informing providers/employers, consumers, consumers’ family members and direct care and support staff about the grant goals and getting feedback was a good learning opportunity that carried challenges. Explanations started with a lot of background information; the worker shortage, which workers were we talking about, why are they important, where did the grant come from and what opportunities did it offer Maine, and what was a ‘guild’ if it wasn’t a union. Talking to colleagues in other states as we were getting this feedback was extremely helpful. An inventory of similar organizations in the country proved very useful in this early stage of the project and informed. (See Appendix 3.) This table was also a helpful reference for Maine PASA organizational development over the next three years.

■ What is a guild? What is an association?

Key decisions were made in the first year that were informed through this process of getting to know the environment, in Maine and nationally. We quickly learned that using the term ‘guild’ was problematic. While a review of guilds and their origins provided a wonderful concept of workmanship, craft and quality that could have been used as a basis for the organization, we also learned that it was not really suited to our target workforce. This conclusion was made following discussions with MIT’s Center for Coordination Science⁶ and Dr. Susan Eaton, noted Harvard Kennedy School researcher on the direct care workforce. There was a link that unions were the American version of the European guild, but even more convincing was the fact that current day guilds were helping independently employed professionals, and the ‘independent’ and ‘professional’

⁵Committee to Address the Health Care Skilled Worker Shortage. (October 2001) Maine’s health care skilled worker shortage: A call to action. Maine Technical College System: South Portland, ME.

⁶Malone, T. (October 4, 2000) Rebirth of the guild. <http://web.mit.edu/newsoffice/2000/oped-1004.html>. Accessed 2001.)

“In recent years, a growing number of groups have emerged to represent the interests of direct care workers and to ensure that the value of their work is more widely recognized and appreciated. Worker associations help members develop their professional, leadership, and advocacy skills through education, networking, mentoring, and other types of support. Unlike unions, professional associations do not negotiate contracts with individual employers, rather they advocate for improvements in wages and working conditions across the sector.”

—Trish Porter, *Direct Support Professional and Life Skills Coach*

were not characteristics we were finding in the direct care and direct support workforce. By January 2002, it was decided that the more commonly understood model of a professional association would replace the venture for the ‘guild’, and would add Maine to the inventory of worker associations in the country.

■ **Is there a worker-directed organization in Maine for these workers?**

For the policy makers and state Medicaid administrators who wrote the grant proposal it was conceivable that an organization, like the Maine Nurses Association, already existed for the aide and assistant level employees. This turned out not to be the case. The best we could learn was that a small number of CNAs had started an association once, but it no longer existed and rumor from the workers was that the CNAs lost their jobs while organizing it. The grant workplan proposed to delegate the project activities, through an RFP process, to an established organization to accomplish the grant goals; to increase the availability of qualified personal with a deliverable for a sustainable, independent Guild that will provide benefits, support, continuing education and advocacy for its members. The exploration to find Maine’s representatives of the national organizations for CNAs and DSPs (the workforce in MR/DD services) located interested individuals but no active groups in the state. No Maine based or national organization was identified that matched the implementation plan; to stimulate the formation of a worker-directed organization through an RFP process to a community organization. The widespread lack of awareness about personal assistants and direct care level staff along with the high degree of skepticism along with apathy about this workforce provided a very mixed assessment of the environment for this grant. There was agreement on the need to recruit and retain quality workers but stakeholders were not very optimistic about the prospects for a worker-directed organization in Maine. These early findings both affirmed the need to pursue the grant goals and the need to revise the strategy for accomplishing them. If we were going to do it, we would have to create the organization ourselves. The decision to request an adjustment from CMS to utilize the funds to start the organization was approved by the Technical Advisory Group early in 2002. This launched a significant effort by the grant staff to learn more about the workforce and to recruit individual workers to have a direct role in the process and future decisions.

■ **What models exist in other states?**

The grant staff identified and contacted worker associations in Connecticut, Iowa, Vermont, Arizona, and North Carolina to learn about their associations, recruiting workers, and their development experience. An inventory of the state-based organizations documented key

information gathered and discussed by Maine PASA early in its formation. (See Appendix 3.) Contact with the Paraprofessional Healthcare Institute (PHI) has been an important resource throughout Maine PASA's development.



Sowing the Soil and Planting the Seed

Questions and Decisions:

- Which workers will be included in the Association?
- How will we reach these workers?
- What would the Association look like?
- What's in a name?
- Who would want to join?
- What partnerships would support the Association?
- How could we engage workers to help with the development?
- How would we recruit members?

■ Which workers will be included in the Association?

The grant referred to the workers as 'personal assistance workers'. The literature on the workforce shortages referred to 'direct care workers' and 'direct support professionals'. The Department of Labor Dictionary of Occupational Titles referenced more than twelve job titles. Workers introduced themselves as 'Life Skills Coaches' and 'Homemakers', titles not listed in the Dictionary. Maine's licensing and Medicaid offices called them Certified Nursing Assistants (CNAs), and Personal Care Attendants (PCAs, a title to be changed in 2003 to Personal Support Specialist (PSS) for new graduates of a revised training curriculum). There were also CRMAs, CNA-Med Tech, MHRT, DSP, Psych Tech and more. (See June 2003 Maine PASA newsletter.) While the grant staff had made a decision to conform to the traditional model of a professional association the task of selecting which worker group would be included and who could be a member was less clear. Other state associations were defined to a particular group of workers. Most had their origin with CNAs (Iowa, Arizona, Florida) with a focus on nursing home and home care providers. Connecticut was the most specialized with its focus on Personal Assistants employed in Consumer Directed Personal Assistance Service and waiver programs. Vermont, which was also in the start up phases was taking the broadest view and considering inclusion of unpaid caregivers in their future association. The Maine grant staff made the decision to be inclusive in defining its target workers based on the grant's origin in disability access, its view of the larger workforce issues being

Direct Care/Support Job Titles

by Diane N., Olga G., and Elise S.

The decision was made to start with a single regional event, then plan the expansion with the worker/ members recruited from the event.

defined in the long-term care literature and its growing appreciation for the common challenges facing every sector of long-term care (nursing home, home care, residential care, elder services, mental health and mental retardation services). The Maine Association would define the workforce broadly to include all people employed in frontline/paraprofessional jobs that assist people with disabilities and elders in all long term care settings. The key terms were ‘employed’, to distinguish the workers from the large group of un-paid/informal caregivers; ‘frontline/paraprofessional’ to distinguish the workers from the RNs and other personnel who likely have a professional association already available to them; the consumer/client group being served by the workers would cover elders as well as people with disabilities of all ages; and the setting of their employment could be facility or home-community based, day services, school or vocational programs.

There have been advantages and disadvantages experienced at all stages of Maine PASA’s development that can be linked to this decision. As the grant staff gained perspective on the broad range of long term care support services being offered, the state’s rebalancing efforts and the growth of home and community based services and acceptance of consumer directed services the inclusive approach appeared advantageous. The strategic advantage to casting a very wide net was important to early development and meant we could maximize our outreach in order to find interested workers and supporters. This gave the grant staff the opportunity to speak to a diverse group of workers and employers to poll their interest and concerns and to recruit their support. The worker group was too broad and their needs too diverse some said. Others saw the advantage of an inclusive organization that would draw on the advances made by Direct Support Professionals to promote self-advocacy and community inclusion, the public’s familiarity with the work of licensed personnel like nurses aides, the ever increasing population of direct care and homemaker workers employed by home health care agencies, and the new wave of personal assistants employed by consumers.

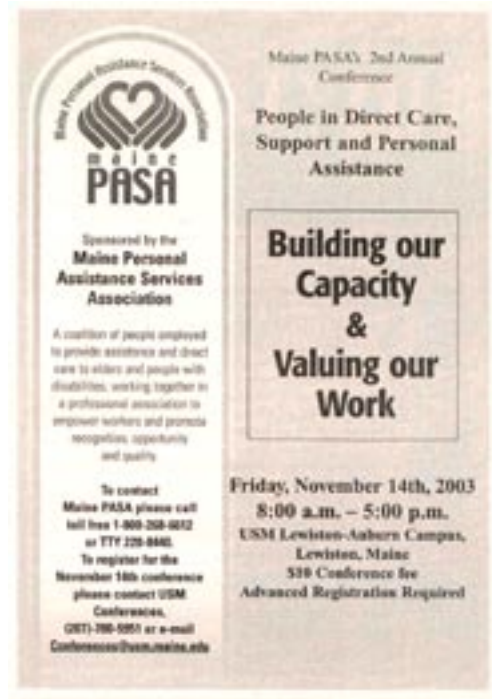
■ How will we reach these workers?

Forming the Association was going to require the direct involvement of a representative group of these workers. Plans were made to hold an event, a forum, to debut the concept for the Association and to get input from workers and supporters. Even though our target worker group was broad and by estimates was over 20,000 people, getting the information/invitation to the individual workers across the state was a significant challenge. While Maine’s CNA registry listed over 30,000 CNAs, both active and inactive, the list was not available to us for direct mailing. No other registry of workers existed. While general newspaper ads, articles and press releases would be helpful, they would not likely inform or motivate people adequately to compete for their time with their work and life activities. The general public appeal would also make it difficult to garner the support of employers to send their workers, or to quell employers’ concern that this was an organizing effort involving unions. A more direct root of communication that would also encourage their attendance was needed. Localizing the event planning was one way to concentrate the outreach efforts. The

decision was made to start with a single regional event, then plan the expansion with the worker/ members recruited from the event. Lewiston, the half way point between Portland and Augusta with a thirty mile radius covering urban and rural areas was selected. The location outside of Portland might prevent branding the association as a Southern Maine 'idea'. Staying south of Augusta assured travel convenience for the major population areas of workers. Now we needed to get notices to the workers and the only targeted way to reach them was to go through their employers. Lists of hospitals, home care agencies, MR/MH service providers were available but getting through administrators to the workers presented a number of barriers. Our early outreach work to contact a diverse array of workers and employers informed our strategy.⁷ A broad base of appeal was necessary for reaching workers and others who supported them; administrators, consumers, other advocacy and nursing groups and state policy makers. The contacts provided opportunities to network, and to get discouraged. The fear of unions closed some doors quickly. Many were curious but uncertain or doubtful about whether the concept of an association would interest the workers. Alpha One, the financial intermediary for consumer-employers agreed to insert event flyers in mailing with a request for consumers to inform their nearly 1,000 direct care and assistance staff.⁸

■ What would the Association look like?

The Lewiston event was held on a Saturday morning. (See Appendix 4.) It was pouring rain but thirty five people, a mix of workers, employers and consumers attended. The evaluations were positive. The greatest outcome was that five direct care workers and one supervisor signed up to help develop the association. Our strategy to provide a breakfast buffet and an option for child care services were supportive. The keynote speaker, Di Findley, Founder and President of the Iowa Caregivers Association, provided both information and an important connection to workers in the audience. The explanation of Iowa's association provided a very clear view of what we were starting in Maine, and why. Di's personal message as a former CNA and the stories from her membership of over 1,000 resonated with the attendees. The clarity of purpose of an association was recognition, advocacy, opportunities for workers and elevated awareness of the value of direct care workers and their work in long-term care. She had the audience with her statement that direct care workers carry a PHD as their measure of importance, "they preserve human



The decision to build the Association to be inclusive of the diverse group of direct care, direct support and personal assistant workers, while noble, became a major challenge when it came to finding a name for it.

⁷Scala, E. (October 21-28, 2002) Direct care and personal assistance. *Employment Times* 4(43):4.

⁸Farber, K. (Winter 2003) Some look to professional organization to ease care worker strain. *One in Five* 2(1):6.

It was extremely important that workers were getting involved and speak personally and professionally about the potential value of the organization to their work and the quality of care to consumers.

dignity”. The introductions from the State and grant staff framed the purpose of the event and provided information about the opportunity the grant provided to build an association for Maine workers. Attendees completed a questionnaire and program evaluation that affirmed their interest for having an Association and guided the grant staff’s next steps. (See Appendix 5, 6 and 7.)

■ What’s in a name?

The decision to build the Association to be inclusive of the diverse group of direct care, direct support and personal assistant workers, while noble, became a major challenge when it came to finding a name for it. To our knowledge there was no one term being used to collectively refer to the larger group of workers, like direct service or support service workers. The use of the word ‘care’ was pivotal. While caregiver and direct care were most familiar, to people with disabilities the word connoted an inability to care for themselves and a need to be taken care of. This was a throw back to the medical model of disability being illness and incapacity. (Insert footnote 9: Bowman, V. (May 2001) Home care, home support, personal assistance: The co-operative model in context. Occasional Paper Series. Online: <http://web.uvic.ca/bcis/research/occasional/paper4-home-care-support.html>. Accessed February 15, 2002.) For Direct Support Professionals who were earning their mark as professionals working with people with mental retardation and/or mental illness “care” also had a medical meaning and did not espouse to the concepts of self direction. “Care” was very familiar to nursing but even home care was shifting to include homemaker and support services. The Association took the broadest and perhaps the ‘politically correct’ term to match its broad definition of the workforce it wanted to encompass; personal assistance services. The group would be called the Maine Association of Personal Assistance Services, Maine PASA.

■ Who would want to join?

The feedback from the event and the immediate involvement of individual direct care, direct support and personal assistance workers provided the base the grant staff needed to move the Association from a concept to an organization. The group of dedicated and motivated key members grew to seven by Spring 2003 and named themselves the ‘founding members’.

Continuing outreach for active members involved appearances, leafleting at other organization’s events, and word-of-mouth news that was being generated since the breakfast forum. Each appearance required a full explanation and assurances about the motives of the Association. It was extremely important that workers were getting involved and speaking personally and

WORK GROUP FORMS THE PERSONAL ASSISTANCE SERVICES ASSOCIATION

After a very successful gathering in October 2002, Maine direct care workers decided that they needed an Association to support their profession. The first work meeting was held on Saturday, December 14, 2002 at the University of Southern Maine — Lewiston Auburn College Campus. A heavy rain and busy holiday season did not keep the group from meeting to discuss why the Association is needed in Maine.

professionally about the potential value of the organization to their work and the quality of care to consumers. These seven people, along with the early support and coordination work of the grant staff were instrumental in the formation of the Association. The 'founding' group worked through regular monthly meetings to establish the organization. (See February 2003 newsletter.) The profile of the founding members illustrates the diversity, and wealth of this start-up group, and the potential this organization has for connecting with thousands of workers across the state.

Trish took on a lead role immediately. Her comfort with being extraverted and direct was matched by her dedication to consumers and her twenty plus years of direct care employment in a variety of settings and organizations. When she joined the Association project she was working as a Direct Support Professional/Life Skills Coach in a residential home for adults with mental retardation and mental illness. Trish had been recently been promoted to a manager position in one of the homes and she had her own sobering statistics to help the Association get focused. To paraphrase her assessment: forty percent of this workforce loves what they do and they care about consumers' quality of life and care. For another forty percent this work is a job. They do the tasks and put in their shift. The last twenty percent are in this work for the wrong reasons and are a risk for their consumers. Trish cared very deeply for the consumers' wellbeing and dignity and the workers who cared and worked to make a difference. While watching Trish present to a group of workers you could see from their expressions that each worker could place themselves and their coworkers into one of the categories. Trish's passion for the Maine Association was that it proposed to support the retention and recruitment of good people, the first forty percent, might motivate the next forty percent that can care, and should care, and should root out the harmful workers immediately.

Kim was a personal care attendant for many years working with elders. When she moved to Maine to raise her daughter and return to her roots she carefully evaluated her options for work. While she had attended school to study marketing and advertising she found opportunities to continue in caregiving and met Trish at work. Kim, like Trish, was articulate as an advocate for quality and dignity and had a great work history and personal experience in direct care. She was also interested in marketing the association.



As a member of management in her organization she was concerned about the prospect of union involvement.

Diane had been working as personal care attendant for a family member and was seeking employment in home care. While quiet in meetings and concerned about her limited experience in relation to other members Diane brought perspective and an interest in writing to the young group.

Susan, a PCA in home care services in Southern Maine was also quiet and attentive to the group. Susan was proud of her accomplishments and her life story can be read on the Maine PASA Our Stories series. In addition to working with people with disabilities and elders in their homes Susan has the experience of caring and managing as the mother of a son with special needs. Susan has been a tried and true founding member who has found personal and professional benefits to continued participation. Shy but always ready with an answer when asked Susan often attended meetings with Olga, a supervisor in her agency. Susan serves as the Co-Chair of the Maine PASA Board of Directors and recently completed advanced training to become a CNA.

Olga states clearly that she attended the Association forum to accompany Susan and to see first-hand what the Association was about. As a member of management in her organization she was concerned about the prospect of union involvement. But, she knew about the Muskie School was coordinating the grant, and as a matriculating student she was also interested in learning more. Olga's support of the Association was immediate and resourceful. By the summer of 2003 Olga had started plans to complete her internship and capstone project working with the association. Olga can speak well about the value of the association to Susan's development and continues to encourage her staff to become members.

Julie approached the Association group with the experience of having looked for an organization for Direct Support Professionals in Maine. Julie was the Maine representative with the National Alliance of Direct Support Professionals and welcomed the additional help to organize the workforce. Julie had worked in manufacturing for years and a plant closing opened the opportunity for her to get trained as a licensed massage therapist. In addition to starting her massage business Julie discovered that working as a DSP was very rewarding. Julie has a zeal for learning and appreciates the group support for building an organization.¹⁰ Julie serves as Co-Chair for the Maine PASA Board of Directors.

Portrait of Julie Moulton

Julie Moulton works as a direct support professional for a resident care agency in Winthrop, Maine. In her role as a direct support professional, Julie provides personal support to adults with mental retardation and development disabilities. We asked Julie to describe some of the challenges associated with her job.

¹⁰Slaughter, A.(2005) Portrait of Julie Moulton. Direct Care Clearinghouse. Online: http://directcareclearinghouse.org/v_det.jsp?res_id=177210. Accessed November 28, 2005.

Roberta knew a lot about organizing and social causes from being active in her community. She also knew a lot about elders and the experience of caring for them. At the time Roberta joined the group she was about to reach her 100th elder. Her stories of home care in rural areas were both alarming and wonderful. Wonderful because they told us about the value of quality in caring and the art of Roberta's approach to knowing her elders. Roberta's interest in writing these stories is part of the Association's legacy. What we learned from them helped to build Maine PASA.¹¹

The Complexity of Caregiving

Roberta Record reflects on her experience in losing a woman she cared for as a personal assistant. She talks about the profound effect that her relationship with the client had on her outlook on life and her work.

Cheryl was a member for the early, 'forming and storming' stages of the group work that started the Association. As a personal assistant in consumer directed employment Cheryl's experience, and perspective of long term care was different than other members. The expressions of advocacy for client dignity and self determination were similar but the terminology, service programs and employment experience were so different that at times it looked like the Association could not be inclusive to all the workers. The demands of her work made it difficult for Cheryl to attend meetings on a regular basis, but her involvement was important to the early formation of the group.

Gail was asked to join the group by Elise Scala, the grant coordinator, to be a facilitator. While Gail was not a direct care or direct support worker her skills in group facilitation, adult education and communications skill development, along with her knowledge of disability as a special education teacher helped the group develop. The transition from a diverse group of individuals to a cohesive group with a common mission took skill and finesse. Making sure the group process was inclusive and worker-directed had a lot to do the members' development as leaders. Gail helped to train the bridge builders, who went off to build the bridge as we were crossing it!

■ What partnerships would support the Association?

The fact that the Real Choices Systems Change Grant, the umbrella to the association project, was awarded to the Maine Department of Human Services gave the grant staff a vote of confidence to proceed. Administrators in all the departments affiliated with long term care and services for people with disabilities were familiar with the issues of workforce shortages and their impact on quality. Their support, as demonstrated through their willingness to attend meetings and support functions and the recognition of the association they carried to multiple meetings of multiple groups

¹¹Record, R. (2005) The complexity of caregiving. Direct Care Clearinghouse. Online: http://directcareclearinghouse.org/v_det.jsp?res_id=162410. Accessed November 28, 2005.

contributed to the name recognition, awareness and credibility of the Association at every stage of its development. The Technical Advisory Group, an oversight committee for the grant projects provided excellent feedback and guidance.

Direct Care Worker Coalition: Another grant funded project that served to be a timely partner to the development of the Association was the Direct Care Worker Coalition. A grant funded the start up of a multi-stakeholder coalition to initiate legislative action of raise the wages of direct care workers. (See February 2003 newsletter and Appendix 8.) Many of the activities and accomplishments

of the Coalition are notable to the outcomes of Maine PASA. Elise Scala, the grant coordinator

Maine Direct Care Worker Coalition: Coordinates State Efforts to Address Worker Shortages

A subcommittee of the Coalition has initiated a bill to the Maine Legislature to increase wages for Direct Healthcare Workers in Maine.

pay/benefits and this increasing worker shortage. They are saying what we as direct care workers have known for years. Now it's at a critical

problem of low wages, limited benefits and long hours. A bill will be introduced to ask the legislature to increase wages and benefits. Hopefully the

was invited to the opening meeting of the Coalition in 2002 and three very significant events occurred. First, the group which was very well represented with providers, state administrators, educators and advocates was being organized to address many of the same issues the Association group was working on. Secondly, it was very striking that, while the coalition members were talking about the plight of direct care workers in low wage jobs without benefits and a turnover rate that was indicative of major problems, no direct care workers were present at the meeting! Third, Elise got the chance to meet Steve Dawson, president of the Paraprofessional Healthcare Institute, the national leader in worker-directed organizations.¹²

The 2002 Coalition meeting was a defining moment for the Association. It was clear that the Association was the likely group to represent the workers in this Coalition, more so than their employers, and representation with well trained workers/members could certainly be a key purpose and function for the Association. While providers/employers were all well intentioned it was not entirely true that their participation would provide the input that the workers themselves could add to the policy discussions that would directly impact them. Lisa Pohlmann, Coalition facilitator, completed the study "Without Care: Maine's Direct Care Worker Shortage" summarizing workers struggles with low wages, difficult working conditions and staff shortages. The report includes key recommendations and can be viewed at www.mecep.org. (See February 2003 newsletter.)

Meeting other organizations through the Coalition, like the Maine Health Care Association, Maine Nurses Association and Maine State Employees Association representatives opened dialogue about workforce issues and mutual interests for the Association.

¹²For more information, visit the Paraprofessional Healthcare Institute's website: <http://www.paraprofessional.org> and the Cooperative Care Associates' website: <http://www.co-opcare.com>.)

Providers/Employers: The outreach work to promote the Association provided a number of opportunities to meet with employers. The fear of unions has been mentioned a number of times as a deterrent for some employers to seeing the potential value an association could offer to the recruitment and retention of their front line entry level workforce. There were however a couple of employers

who responded in quite the opposite way. Home Resources of Maine, Inc. (renamed Home Care for Maine in 2005), a large

home care agency and provider of non-medical homemaker and assistance services has been a major supporter of the Association. The CEO, Susan Rovillard made significant contributions to the early development by notifying her 400 plus employees of events and notices and supporting her employees to be active participants. Olga Gross, Administrator with Sandy River Home Resources was also a major supporter.

SPECIAL REPORT

Without Care: Maine's Direct Care Worker Shortage

Maine Center for Economic Policy, Author Lisa Pohlmann

Regional peers: Peer organizations in the New England region, extending to Connecticut, were great sources of information and support in the early days of the Association. Vermont, North Carolina and Connecticut were utilizing Real Choices Systems Change Grant funds to build worker associations. Frequent conversations were held to exchange information and Deb Barisano, the founder of the Connecticut Association of Personal Assistants came to Maine to provide assistance and to make a presentation. The Iowa Caregivers Association was mentor and peer to all of us.

National peers: The Paraprofessional Healthcare Institute has been a leader and major support for Maine and the other states in their efforts to develop associations and the workers to represent them. The Direct Care Alliance (DCA) was established by PHI to support coalitions and associations and has become a valuable partner for Maine PASA and other state associations. The National Alliance for Direct Support Professionals (NADSP) is also a leader and model organization.

Grant partners: The Real Choices grant, with its field of grantees and technical assistance organizations provided an important resource for support. The staff in Maine at the National Academy for State Health Policy and the TA group at Rutgers provided funding and support to build bridges of support and partnership across the states.

“Maine PASA has given us voice.”

“Maine PASA has provided a coalition for affecting change.”

“I have had the opportunity to go to conferences that have exposed me to the wider issues of elders.”

— *Direct care workers responding to the value of Maine PASA*

■ How could we engage workers to help with the development?

The grant funds were instrumental in supporting the development of the Association. The grant coordinator supplemented the part-time hours allocated to her position by utilizing funds for stipends to compensate the direct care workers for their time spent at meetings and Association activities and for travel expenses. This was necessary given that a number of the founding members had to lose work hours in order to attend meetings. The cost of travel was also recognized as significant and a mileage reimbursement was given for documented travel expenses for meetings and events. Were we paying workers for their time? Yes, at \$10/hour for meeting time only it was not a money making venture and seemed reasonable given that many of our meetings were on Saturdays to minimize the conflict with client schedules.

■ How would we recruit members?

The founding member group spent many of their meetings discussing what the Association would look like, what it would do and how people would be recruited. While the discussions seemed circular and non-productive for some members the decisions made about the Association formed the foundations of the structure and function of the organization. The development of the Maine PASA name, logo and mission statement grew from these discussions.



The discussions were also helping the members to become more fluent and confident with the idea of an association and how to describe it to others.

A health care worker job fair scheduled in the region provided a good opportunity for the members to practice. The Association reserved a table and members selected time slots over a full day schedule to staff it. Members paired up to support each other and spent time preparing for the presentations. Scripts with the major points and role play sessions were practiced at a meeting before the fair. Materials and a sign up sheet were also prepared for the display. This was a milestone event for the founding members and the Association and the response from attendees and other organizations was favorable.

Maine PASA Features New Logo and Mission

Thanks to the input of many, the hard work of the development team, and an artist's touch the logo and statements of purpose for the Maine Personal Assistance Services Association are ready for distribution. The message is that Maine has an organization that recognizes and supports direct care/

Job Fair Preview Session

Members of Maine PASA were well represented at the Health Care Job Fair in South Portland on May 19th. The brochures and sign up sheets, boosted by the enthusiasm of member outreach successfully informed many Fair attendees and recruited over thirty new members!



The materials and the workers' voices, and a growing number of events to present them were pressing the founding members to be prepared. Name tags, business cards were needed. The scripts were not needed anymore. These members were ready to go out and talk. The brochure and newsletter were the tools they needed. Another annual event and a website were needed. (See Appendix 9.)

**Announcing the
Maine PASA website!!**

*Currently under construction!
Coming to a computer near you!*

www.MainePASA.org

Sprouting: Developing Structure

Questions and Decisions

- What structure will support the development goals of the Association?
- What role did the workers have?
- Are we professionals?
- How will Maine PASA establish itself and become recognized?

■ What structure will support the development goals of the Association?

The founding members met monthly to oversee the combined work of organizational development and 'operations'. The work of Maine PASA now involved the production of the newsletter, a website, tending to the phone calls and the member database, preparing for and making presentations, attending meetings, finding opportunities for workers to serve as representatives, finding the workers to fill the seats and supporting them to be informed representatives. Balancing Maine PASA needs and ambitions with the need to directly engage the workers was critical to its mission and to its members. The role of the paid grant staff, while still part-time, continued to be instrumental in facilitating the group's development process and output. The active members and the staff were critical to recruiting more members and to the development of its future. As the third and final year of the grant approached it was clear that Maine PASA's future was going to depend on its own sustainability as an organization. The grant goal was a deliverable for a sustainable, independent Guild that will provide benefits, support, continuing education and advocacy for its members. The immediate goal was non-profit status and the structures necessary to achieve it.

The applications for incorporation in the state and tax exempt status with the Internal Revenue Service guided Maine PASA's planning to achieve this goal. A clear mission statement and an established Board of Directors were required. A consultant with expertise in non-profit organizations was very helpful for guiding the Maine PASA meetings to review important questions about its mission and purpose. It was necessary for the group to review the differences between an advocacy and charitable organization and to assess the implications of categorizing Maine PASA as one or the other. The decision was made that non-profit, tax exempt, 501(c)(3) status fit both the intended purpose and activities of the group. This status would be necessary to access grants to finance Maine PASA's operations, programs and its future.

• **IRS Terms and Requirements for Tax Exempt Status**
• (<http://www.irs.gov/instructions/i1023/index.html>)

• **■ Who Is Eligible for Section 501(c)(3) Status?**

• Organizations organized and operated exclusively for religious, charitable, scientific, testing for public safety, literary, or educational purposes, or to foster national or international amateur sports competition, or for the prevention of cruelty to children or animals are eligible to file Form 1023 to obtain recognition of exemption from federal income tax under section 501(c)(3) of the Internal Revenue Code.

• **Qualification of a Section 501(c)(3) Organization**

• There are two key requirements for an organization to be exempt from federal income tax under section 501(c)(3). A 501(c)(3) organization must be organized and operated exclusively for one or more exempt purposes.

• **Organized.** An organization must be organized as a corporation (including a limited liability company), trust, or unincorporated association. The organizing document (articles of incorporation if you are a corporation, articles of organization if you are a limited liability company, articles of association or constitution if you are an association, or trust agreement or declaration of trust if you are a trust) must limit the organization's purpose(s) and permanently dedicate its assets to exempt purposes.

• **Operated.** An organization must be operated to further one or more of the exempt purposes stated in its organizing document. Certain other activities are prohibited or restricted, including, but not limited to, the following activities. A 501(c)(3) organization must:

- a. Absolutely refrain from participating in the political campaigns of candidates for local, state, or federal office.
- b. Absolutely ensure that its assets and earnings do not unjustly enrich board members, officers, key management employees, or other insiders.
- c. Not further non-exempt purposes (such as purposes that benefit private interests) more than insubstantially.
- d. Not operate for the primary purpose of conducting a trade or business that is not related to its exempt purpose(s).
- e. Not engage in activities that are illegal or violate fundamental public policy.
- f. Restrict its legislative activities.

Legislative activity. An organization does not qualify for section 501(c)(3) status if a substantial part of its activities is attempting to influence legislation.

For this purpose, “legislation” includes action by Congress, a state legislature, a local council, or a similar governing body, with respect to acts, bills, resolutions or similar items (such as legislative confirmation of appointive offices). Legislation also includes action by the public in a referendum, ballot initiative, constitutional amendment, or similar procedure. Legislation generally does not include actions by executive, judicial, or administrative bodies.

Organizations may involve themselves in issues of public policy without being engaged in legislative activity. For example, organizations may conduct educational meetings, prepare and distribute educational materials, or otherwise consider public policy issues. Similarly, an organization may appear before a governmental body to offer testimony about a decision that may affect the organization’s existence.

Every organization that qualifies for tax-exempt status under section 501(c)(3) is further classified as either a public charity or a private foundation. For some organizations, the primary distinction between a public charity and a private foundation is an organization’s source of financial support.

“Maine PASA have given us a voice.”

“Maine PASA has provided a coalition for affecting change”

“I have had the opportunity to go to conferences that have exposed me to the wider issues of elders.”

— *Direct care workers responding to the value of establishing an association*

The founding members spent a number of meetings learning about these terms and requirement and working on the mission statement, fine tuning it to clearly express its intentions to its members, supporters and the general public. The results formalized Maine PASA’s course for the Board and its future development. The mission statement was published in a new brochure and the IRS application for tax exempt status was completed. As the news clipping from the Maine PASA newsletter notes, the work completed by the group produced major outcomes in support of the grant objectives and the future of the organization. (See Appendix 10.)

■ What role did the workers have?

Transitioning Maine PASA from a grant project to its own organization involved changing the role of the ‘Founding’ members to ‘Board’ members. This was a significant transformation and Maine PASA’s success says a lot about the members who were directly involved as well as the importance of staff support. The workers and support members who agreed to continue as Board members were very important to its progress. Completing the necessary steps for non-profit status required endurance, skills and vision. Most of the members (the worker members as well as some of the support members and staff) did not have experience working with non-profit boards or the discussions on strategic planning and organizational structures, but they were certainly willing and able to learn. The grant staff provided leadership and technical assistance through the process. There were numerous times when everyone tired of the discussions of mission statement and bylaws but all agreed on the value of getting the work done. The bylaws were drafted and approved with the consultation of an attorney. There was consensus, and it was written into the bylaws, that more than half the board members would be direct care or support workers, and that the board would be voluntary. This was also a requirement for the tax exempt status and for the workers involved it meant they would no longer be paid for their time to participate, as they had been before the Board was established. This changed one of the operating commitments that Maine PASA had set in its early days, that it would recognize the value of workers’ time and pay them for meeting hours, as the others around the table enjoyed. Many of the founding members were juggling work hours and sometimes losing client hours/paid time in order to attend to PASA business. For the workers who accepted the Board positions this was a commitment they were prepared for. Their input as active members, serving as Board Chair and Co-Chair, was, and continues to be, instrumental in the organization. These worker members,

Maine PASA has a mission

The mission of the Maine Personal Assistance Services Association is to build recognition and opportunity for the direct care, direct support, and personal assistance workforce through education, professional development, and public awareness.

Maine PASA has a purpose

Building Capacity by Providing Opportunity

The Association will promote professionalism and development for the direct care, direct support, and personal assistance workforce to support the highest quality of life for elders and people with disabilities.

Maine PASA activities and programs

- Build Recognition: To raise the awareness in public, employment, and policy settings about the value of direct care, direct support, and personal assistance work and workers.
- Build Opportunities: To provide opportunities for workers to network, to build connections, to participate, and to gain knowledge and skills to attain personal and professional goals.
- Promote Professionalism: To advocate for quality jobs and to promote quality direct services with dignity and consumer choice.

along with all the other Board members rose to the occasion. Board membership, consistent with the organization's mission provided members an opportunity to learn and grow. There have been discussions on how best to meet the needs of the Board while not setting skill and experience requirements that will exclude worker involvement and that allow for development. Acknowledging the importance of having workers' voices that represented a number of work sectors (nursing home, assisted living, home care, direct support for people with developmental disabilities and personal assistants in consumer directed employment) Maine PASA looked to fulfill its board skills and expertise needs through its executive director, other Board members and the use of consultants. The goal of having direct care and support workers in lead positions needs to be supported through a development plan. Maine PASA strategically planned its development of Chapters and positions for members to serve on state committees to be the opportunity for members to develop the leadership skills to be future Board members and leaders. (See April/May 2004 newsletter.) Familiarity with Maine PASA's mission and purpose, a commitment to the mission and the responsibilities of the Board, and comfort with speaking in small groups and representing the interests of the diverse workforce of direct care and support workers and are the primary skills needed. The founding members also demonstrated the value and necessity for other skills, the ability to learn and the willingness to take a chance and speak up for what they see as important for consumers/clients, coworker, and themselves. Building these skills and fulfilling organizational roles, while critical to Maine PASA's development objectives, has been new growth added on to the remarkable skills these workers demonstrate every day in their work. Our Stories, the oral history project, was conducted to draw out the workers' voices and raise awareness about the work and workers. These stories tell us about the skills workers can bring to the mission and vital role they have in long term care and support. (See Appendix 11.)

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.

A Call for Stories

Maine PASA would like to feature stories about people who are direct caregivers, direct support professionals and personal assistants on our website. We want to recognize the people who do the work, be able to tell others about the work, the dedication and the true value of these jobs, and the people who do them. If you know a co-worker or friend who is employed to provide assistance or direct care to an elder or person with a disability who you think does a great job please write and tell us about what they do. Why would you want this person helping you or caring for your family member? We would like to hear about your work too.

“One person by themselves many not be able to make changes. Affirms the people who provide support and helps employers support workers.”

“Provide a forum for celebrating and recognizing the workers and the work.”

“To reduce isolation.”

— *Direct care workers responding to the value of establishing an association*

■ Are we professionals?

As Maine PASA built its recognition and activities as an association, the clearest model for development was the professional association. From the early days that Maine PASA took this direction, away from the Guild or union, the question was raised about whether direct care and support workers were in fact “professionals”. The best answer is presented in Roberta Record’s article, written when the Association was just getting starting and forming its identity. While Maine PASA’s development as an organization, the performance of its board members and the competency presented through their stories of work in long term care should affirm this, there continue to be questions about the status of this workforce. The affiliations with the health care model for long term care relegates direct care staff, the aides, to be less than nurses, but gives them recognition of having one hand over the line as “paraprofessionals”. There are also workers, the personal assistants employed by consumers, along with their consumers and advocates who consider the Association, and the trappings of professionalism like training and education, as a ‘medical model’ that takes away from the relationship and consumer direction. And, many direct care and support workers aspire to ‘preserving human dignity’ and the importance of working with people is far more important than a profession that requires them to be climbing a career ladder. Maine PASA’s membership is inclusive of people with all these views and it continues to find common ground by emphasizing the need for recognition and support for quality jobs and quality care/support for all workers.

■ How will Maine PASA establish itself and become recognized?

Maine PASA’s development has been both internal and external. Building Capacity by Providing Opportunity was the purpose statement that guided this development. This purpose presented a triple challenge. Maine PASA needed to become recognized as having legitimacy and value in long term care

Editorial: Am I A Professional?

by Roberta Record, PCA, and Maine PASA member

Maine PASA Gets Tax Exempt Status

The U.S. Internal Revenue Service approved Maine PASA’s application to become a 501c(3) organization in January 2005. This is another important milestone for Maine PASA and follows the serious work done by the Board of Directors to write a mission statement and business plan that tells how the organization will serve its members and the general public. Being approved to be a tax exempt 501c(3) and an incorporated non-profit organization in Maine are important demonstrations of Maine PASA’s status and suitability to serve its members, affiliates and funders. This is a responsibility and a trust that the Board and Executive Director will carry out. Maine PASA welcomes contributions, including financial donations for designated support activities. These contributions are now tax deductible! Please contact Roy Gedat, Executive Director, for more information.

Maine PASA Representatives Present in Baltimore



Roberta Record, PCA with Bridge Nene Cox, and Julie Martin, DSP with Support Services, represent Maine PASA and were a part of direct care and support workers at a national conference.

“People in
part, care
care workers
cannot get
wonderful
the attitude
without ac-
knowledg-
ment of
service like
any kind of
good work of
Attorneys
and what’s
silly to talk.

services, with employers and state administrators; it needed to be seen as relevant and worthwhile for direct care and support workers; and the workers needed to be directly involved as representatives of the membership.

Maine PASA has grown with a core group of active members, a growing number of total members (both primary/direct care and support workers and support members) and a network of supportive state and national organizations. The brochures, member-to-person contact, annual events and occasional staff meetings with employers have been getting the word out. While the Maine PASA name has become familiar to more employers the degree to which they embrace it continues to run the full range of total support and promotion of it to their employees to ambivalence and complete rejection. The out-spoken support of a couple of well respected administrators has, and continues to be, an important source of recognition. The website and newsletters are making a presentation that adds both visibility and legitimacy to the organization. They provide a consistent message and a professional look that have been useful for communicating with employers, potential members and affiliated organizations. Membership has steadily grown. By 2003 Maine PASA was rooted and developing and was beginning to establish itself professionally. This is illustrated in the timeline in the listing of events and presentations that continued into 2004 and 2005. The increased activities and Maine PASA's response to them have been building a momentum that is best described by the metaphor used in this report. The growth of members, their individual capacity along with the capacity of the organization took a while to grow roots and sprout. Now, it is organized and beginning to grow above ground.

Continuing grant support both finances this effort so there is no cost to members and carries an important link to state and federal programs that help explain its value. Over the four years that Maine PASA has grown, other organizations and initiatives have also addressed concerns for the direct care and support workforce. The events and initiatives of other organizations, in Maine and nationally, have begun to target direct care workforce recruitment and retention. The Maine Direct Care Worker Coalition provides an important workgroup for Maine PASA. Its members now represent workers at the table, along with the union, and have the opportunity to provide input to important policy decisions. This type of involvement continues the recognition and capacity building that feeds the growth of Maine PASA and its members.



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.



Productivity: The Fruit and Blossoms

There are numerous products that grew from Maine PASA's activities. The illustrations in this report reference many of them: the newsletters, website, presentations, attendance to meetings, statements at public hearings, lists of accomplishments, displays, annual events, presentations, 501(c)(3) status, member development, participation in other groups, Our Stories, Chapters, partnerships with PHI/DCA, formal structures: Board, non-profit status (See Appendix 12.), Maine PASA Connections, Executive Director, funding development, evaluations/surveys to get input, membership on committees, increased membership numbers and grant applications. The most notable outcome is the growth of people and relationships. It's in the stories and comments, and in the lives

of the workers who joined Maine PASA and participated in its opportunities. It's Susan Tucker, who grew personally from a quiet observer to a representative and co-chair of the Maine PASA Board, and returned to school to achieve her certification to be a nursing assistant. It's Roberta Record who started a journal to chronicle her work in home care with elders and to begin publishing writings based on those experiences. It's Julie Moulton, interested and supported to advance in her job to advocate for people with disabilities and her interest to organize Direct Support Professionals. In 2005 Maine PASA has new members active on its Board and representing Maine PASA in the state and nationally. These people are blossoming, and Maine PASA gets stronger. The diversity of its members adds to its future and sustainability.



Maine PASA Board Appoints an Executive Director

The Maine PASA Board of Directors is pleased to announce the appointment of Roy Gedat to the position of Executive Director. The position was advertised in December and recruited many excellent candidates. Roy was selected for his extensive experience in managing a non-



Future Growth

Maine PASA surpassed the 600 member mark in 2005 and continues to gain members and support. The expectations of the members is growing as the challenges to long term care and support programs grow. Cuts in funding, rising fuel costs and a changing political and financial environment are both threats and opportunities to the workers, consumers and to Maine PASA. The sustainability of Maine PASA will be dependent on its continued growth and strength. This translates from its parts, roots-stem-branches, to the realities of people, time and money. The grant provided the start for Maine PASA to form and build its internal capacity. Its success in doing this established some important relationships that will influence its future. Partnering with the Paraprofessional Healthcare Institute (PHI), the Direct Care Alliance (DCA), the Maine Direct Care Worker Coalition, and other associations is providing crucial sources of support for securing its future. The affiliations have provided opportunities to participate and grow through the activities like presentations and legislative initiatives. They have also provided connections to grant opportunities and future funding. As a non-profit organization, Maine PASA will continue to rely on grant funds to support its growth and will therefore compete with many others to get the resources it needs to operate and accomplish its mission. During this last year of operation under the Real Choices grant, Maine PASA has positioned itself within partnerships and a strong base of members to grow into the future.

Health Insurance Outreach Help Needed

Maine PASA is concerned about health care coverage for direct care, direct support staff and personal assistants. Our members have told us this is one of their top issues and that it can make the difference between staying in this line of work and leaving to find a job with benefits. We need to find and keep good people in these jobs! And, we know that this is only going to happen if we improve the jobs. One way we can do this is to make sure employers (agencies and consumers) and their direct care and personal assistants have good information and know what the benefit options and costs are.

Maine PASA is working with Consumers for Affordable Health Care and the Health Care for Health Care Workers Initiative, a national effort sponsored by the Paraprofessional Health Care Institute to offer information and support. Employers watch your mail for announcements of meetings in your areas and the Small Business Newsletter with information about DirigoChoice. Maine PASA members: you can help! We are recruiting direct care employees, direct support professionals and personal assistants to attend trainings and assist with outreach that will help other workers to find health coverage. Call Elise 228-8423, or Roy (207-890-0773 or 800-268-6612) to find out how you can help.

The Illustrated History of Maine PASA:

Establishing an Association for Direct Care and Direct Support Workers in Maine



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Excerpted from the Proposed Quality Choices Cooperative Agreement between Bureau of Medical Services, Maine Department of Human Services and Edmund S. Muskie School of Public Service University of Southern Maine (Submitted January 9, 2001).

c-3. Personal Assistance Workers' Guild

Muskie PD: Elise Scala
DHS Lead: Christine Zukas-Lessard

Goal: The goal of this project is to increase the availability of qualified personal assistance workers in Maine.

Description: In collaboration with the Access and Availability Technical Advisory Group, Muskie staff will draft and issue an RFP to provide start-up funding for a Personal Assistance Services Workers' Guild. The goal will be to develop a guild, which will provide its members opportunities for networking, professional training, and links to higher education, and possibly sponsorship of group benefits such as health and disability. Because an independent guild may become an advocacy organization in matters of wages and other policies, the Guild will be expected to become self-sustaining through dues, grants or other funding. Project activities will include:

- convene Access and Availability Technical Advisory Group to advise in the development of RFP;
- review literature and experience of worker organizations in Iowa, Wisconsin, California and elsewhere. Invite experts from other states to meet with interested Maine parties;
- develop guild model;
- issue RFP for one or more contractors to develop guild(s) or similar organization(s);
- implement guild(s) or similar organization through contractor(s); and
- provide technical assistance to the contractor as needed to implement a sustainability strategy for the guild.

Deliverables	Products	Due Date
Literature/best practices review of PAS organizations		9/02
Meet with/convene a conference of stakeholders and national experts		9/02
Develop PAS Workers' Guild model and issue RFP to develop the guild		10/02
Implement Personal Assistance Workers' Guild through contractor(s)		10/03
Document lessons learned		9/04

Appendix 1 ■ Quality Choices Cooperative Agreement Excerpt

Workplan

Year 1 Tasks and Staff/Position	O 01	N 01	D 01	J 02	F 02	Ma 02	A 02	My 02	Jn 02	JI 02	A 02	S 02
Literature review; phone interviews with experts in other states; identify national models for project activity (ES, SB, KP)		•	•	•	•	•	•	•	•	•	•	•
Meet with/convene Access and Availability Technical Advisory Group (ES, SB, LML, Program Manager TBA, Consultant)				•		•		•		•		•
Meet with/convene conference (ES, SB, Consultant)				•	•	•	•	•	•	•	•	•
Develop PAS Workers' Guild Model and issue RFP (ES, SB)		•	•	•	•	•	•	•	•	•	•	•
Document lessons learned (ES, SB)				•	•	•	•	•	•	•	•	•

Year 2 Tasks and Staff/Position	O 02	N 02	D 02	J 03	F 03	Ma 03	A 03	My 03	Jn 03	JI 03	A 03	S 03
Meet with/convene Access and Availability Technical Advisory Group (ES, LML, Program Manager TBA)		•		•		•		•		•		•
Develop PAS Workers' Guild Model and issue RFP (ES)	•											
Oversee contractor implementation of Guild (ES)		•	•	•	•	•	•	•	•	•	•	•
Provide technical assistance to contractor (ES)		•	•	•	•	•	•	•	•	•	•	•
Document lessons learned (ES)		•	•	•	•	•	•	•	•	•	•	•

Year 3 Tasks and Staff/Position	O 03	N 03	D 03	J 04	F 04	Ma 04	A 04	My 04	Jn 04	JI 04	A 04	S 04
Oversee contractor implementation of Guild (ES)	•	•	•									
Provide technical assistance to contractor (ES)	•	•	•	•	•	•	•	•	•	•	•	•
Document lessons learned (ES)	•	•	•	•	•	•	•	•	•	•	•	•
Meet with/convene Access and Availability Technical Advisory Group (ES, LML, Program Manager TBA)		•		•		•		•		•		•

Year 1 Staffing: Elise Scala (Project Director), Stuart Bratesman, Lisa Marie Lindenschmidt, Karen Pearson, Program Manager TBA

* Note: For a listing of staff days on project, please see Section III.

Benefits to the University: The shortage of direct care workers, combined with the increased need anticipated as baby-boomers age, has created national and state interest in ways of enhancing the desirability and status of direct care as a profession. This project will provide the Muskie School with an opportunity to contribute in this field by developing and testing one model for addressing this need. This project provides the Muskie School with an opportunity to collaborate with the University's School of Nursing, with national experts in the field, and with multiple stakeholders statewide. The knowledge gained from this work will enrich the academic programs as well as provide a foundation for further development and research.

Access Technical Advisory Group (TAG) Members

Patricia Albert-Dehetre, Elder Independence of Maine
Pam Allen, Elder Independence of Maine
Linda Ault, Bureau of Medical Services
Myra Champagne, Brain Injury Association
Alice Conway, Developmental Disability Council
Josie Coogan, Consumer Advocate
Stephen Crate, Bureau of Rehabilitation Services
Stephanie Crystal Wolfstone-Francis, Consumer Advocate
Eric Dibner, Division of Vocational Rehabilitation
Barbara Donovan, Office of Passenger Transportation
Alison Dyer, Consumer Advocate
Karen Evans, Disability Rights Center
Cary Gifford, Consumer Advocate
Caryl Harkins, Sweetser
Steve Hoad, State Rehabilitation Council for the Blind and Visually Impaired
David Hodgman, Consumer Advocate
Harry Hurlbert, Consumer Advocate
Lorraine Kaloguros, Consumer Advocate
Tonya Labbe, Oversight Committee for Children's Mental Health Services
Rod McInnes, Division of Vocational Rehabilitation
Linda Meyer, USM Department of Recreation and Leisure Studies
Jeffrey Mosman, Different Abilities, Inc.
Diane Sevigny, Southern Maine Parent Awareness
Pam Studwell, Consumer Advocate
Deb Parker Wolfenden, Funding Research and Consulting
Debbie Rogers, Maine Parent Federation
Rebecca Weinstein, Developmental Disabilities Council

Appendix 3 ■ Maine PASA Project Worker Association Reference Information

Maine PASA Project: Worker Association Reference Information

State	Arizona	Connecticut
Contact	www.directcaregiver.org Judith Clinco, RN, Pres. P.O. Box 65597 Tucson, AZ 85728-5597 E-mail: Judy@directcaregiver.org Tel: (520) 325-4870 Fax: (520) 327-3967	www.ctapa.org Deb Barisano, Founder & Dir. Connecticut Assoc. of Personal Asssts. P.O. Box 316 Manchester, CT 06045-0316 E-mail: info@ctapa.org
Official Name	Direct CareGiver Assoc.	Connecticut Assoc. of Personal Asssts.
Founded	December 2000	2002 (<i>when grant period began</i>)
Description	Based on employer-sponsored model. Nat'l. not-for-profit organization which seeks to bring innovation, solid planning, & creativity to the task of "professionalizing," & certifying individuals interested in becoming direct caregivers.	The Connecticut Assoc. of Personal Asssts. was created by personal asssts. for personal asssts. It's based on & promotes the consumer-directed model.
Status	NP 501 (c) 3	
Mission, Vision & Values	Recognizing, honoring, valuing, & training direct caregivers; thus assuring that those who need care are treated with dignity, compassion, & skill.	Shifting the balance through mutual support, advocacy, & outreach.
Goals	To increase the number of trained qualified caregivers to care for elder & disabled individuals.	Raise professional status by education, outreach, & advocacy. Promote the development of large, competent workforce.
Leadership Structure	12 on Board of Dirs. (<i>includes 2 direct caregivers who graduated from our training program & 4 on Exec. Comm.</i>). Program Coord. handles day-to-day operations.	
Staff Paid?	Yes	2. Coord. & Employer Liaison
Board Mtgs.	10 times/yr.	Monthly Mtgs.
Activities & Printed Materials	Caregiver resource ctr.: career counseling, training, job placement, continuing education, professional development, & ongoing support to the direct caregivers. Creating a nationwide accreditation model for raising the standard of care provided by direct caregivers who are employed in the industry or work privately.	Support system of monthly mtgs., qrtly. newsletter, brochure, & web site, & legislative activity for health insurance benefits for workers.
Area Covered	Tucson, AZ based. Metropolitan area.	Connecticut
Operations & Budget	Provider membership dues, tuition, job placement fee, job training grants, & private donations.	Funded through a grant from The Connecticut Council on Dev. Disabilities. 1-yr. grant of \$22,500.
Membership	12 healthcare employers, 8 supporting organizations, & 350 direct caregivers who are employed by our healthcare provider members.	Mailing list of 150 names (<i>includes 60 PCAs</i>).
Challenges to Getting Started		Fear of union. It's hard to get personal asst. addresses due to confidentiality concerns.

Appendix 3 ■ Maine PASA Project Worker Association Reference Information

State	Direct Care Alliance	Florida
Contact	Patsy Harris, Exec. Dir. Direct Care Alliance Paraprofessional Healthcare Institute 349 East 149 th St, 10 th Floor Bronx, NY 10451 Tel: (718) 928-2040 Fax: (718) 965-5565 E-mail: Patsy@paraprofessional.org Another E-mail Contact: carm@paraprofessional.org	Terry Bucher, LPN, Pres. Florida Assoc. of Nurse Assts. 6039 Cypress Gardens Blvd. Winter Haven, FL 33884-4115 Phone/Fax: (863) 318-8495 E-mail: fana266@es.com http://hcassidy.tripod.com/FANA/FANA.html
Official Name	Direct Care Alliance (DCA)	Florida Assoc. of Nurse Assts., Inc.
Founded	1999-2000, 1 st Exec. Dir. hired in Feb. 2003.	1995 as education support group. 1997 – FANA.
Description	Services consumers, workers, & concerned providers of LTC.	Assoc. for nursing assts., regardless of title or place of employment.
Status	Expected to become 501(c) 3 by Sept. 2004.	NP.
Mission, Vision & Values	Currently being drafted to improve the quality of care for consumers through the creation of higher-quality jobs & working conditions for direct care paraprofessional workers. The DCA promotes recognition that direct care paraprofessionals are the foundation of good care, particularly for long-term care clients.	The mission is to bring FL nursing assts. together in mutual support & recognition of their contribution to the health care field, to enhance skills & professionalism by providing & encouraging ongoing education, encouraging adherence to a code of ethics, as well as awareness of regulations governing their profession; thus furthering the compassionate & efficient care of the sick, elderly, needy, & infirm. Values on-going education, formal training, & certification.
Goals		Enhance skills & professional status of workers.
Leadership Structure	Full-time Exec. Dir. PHI provides admin support, 6 on Exec. Committee (2 workers, 2 consumers, 2 providers), & 3 other standing committees.	Pres./Dir. (<i>founder at present</i>), “Normal” officer structure (VP, treasurer, secretary). 12 on Board of Dirs. (Admin., Educators, RN, LPN, & CNAs representing Assisted Living), LTC, Hospice, Educators, DON, & HHA.
Staff Paid?	Stipends to direct care workers for participation & expenses reimbursement.	\$500 stipend/mo. for Dir.
Board Mtgs.	Exec. Committee meets qtrly., general mtg. 1/yr.	Qtrly. for regular mtgs. & a goal planning mtg. every Jan.
Activities & Printed Materials	Networking & support.	Annual Oct. convention. Membership cards, educational programs @ no cost to members, in-service certificates, scholarships, networking, committees, serve as chptr. officers/board. Recognition, events, awards, leadership class, dinner mtgs., & home in-service studies. Newsletter 3/yr. & info. updates for programs. 13 local chptrs. providing educational programs for nurse assts.
Area Covered		34 counties of the state are represented (<i>over 1/2 of counties in the state</i>) & are spread over the entire state.
Operations & Budget	Supported by Paraprofessional Healthcare Institute & Ford Foundation until it becomes NP 501 (c) 3.	Membership dues: \$20/individual +/-or supportive member, \$15/student, \$20/supporter, \$150/provider, & \$125/vendor.
Membership	1 PCA, 3 CNAs, 7 providers, 4 consumer organizations, 3 unions, & “Friends of DCA” (<i>informal members</i>).	350 members from 28 of 65 counties.
Challenges to Getting Started		Fear of union. Getting workers to act responsibly as professionals.

Appendix 3 ■ Maine PASA Project Worker Association Reference Information

State	Iowa	Maine
Contact	Di Findley, Dir. 1117 Pleasant St., Suite 221 Des Moines, IA 50309 E-mail: iowacga@aol.com Tel: (515) 241-8697 Fax: (515) 241-8587 www.iowacaregivers.org	Maine PASA P.O. Box 1881 Portland, ME 04102 E-mail: scala@usm.maine.edu Tel: (800) 268-6612 TTY (207) 228-8440
Official Name	Iowa CareGivers Assoc.	Maine Personal Assistance Services Assoc.
Founded	1992	Fall 2002
Description	Professional Assoc. for CNAs, Home Care Aides, Patient Care Technicians, & other direct care/support workers who deliver 80%-90% of the care in Iowa's nursing facilities, home care agencies, & in many other health care settings.	Assoc. for personal assits. & direct care workers include DSPs, CNAs, PCAs, HHAs, PSS, BS, MHRs, life/job coaches, homemakers, & all others employed to provide direct support services.
Status	NP	Fall 2003 plan for NP & 501(c) 3 applications.
Mission, Vision & Values	Mission: Enhance quality of care through dedication to the direct care worker. Values opportunities for personal & professional growth & development, respect by community, livable wages, job recognition with training criteria, professional standards & competency requirements, & opportunities to network. Speak on behalf of profession, & have voices heard in policy making & in the community.	Mission: Maine PASA, a coalition of people employed to provide assistance to persons with disabilities & to elders. Maine PASA is organized to empower workers, build opportunities, respect human dignity, & improve quality of jobs.
Goals	Enhance quality of care by providing education, support, & recognition for direct care worker.	To form a coalition, empower workers, build opportunities, respect human dignity, & improve quality of jobs.
Leadership Structure		Currently a grant project with a part-time Coord. & a development team of PA, DC, & DSP workers.
Is Staff Paid?		Yes
Board Mtgs.		Development group meets monthly.
Activities & Printed Materials	Provides education, information, support, & advocacy for those who perform direct resident, patient, +/- or client care. Conducts market research relative to staff recruitment & retention. Newsletter, brochure, & web site.	Legislative activities, outreach, & coalition building. Membership on state coalition & policy work groups. Brochure distribution, presentations, & bi-monthly newsletter. Conference planning. Grant development.
Area Covered	State-wide	Mtgs. in lower region of state. Mailing list is statewide.
Operations & Budget	Membership dues: \$10/worker, \$25/associate members (DOAs, educators, & administrators), & fundraising.	No membership dues at this time. CMS Grant.
Membership	250 members	12 on Development Team. Mailing list is 240.
Challenges to Getting Started	Fear of union.	Worry of union, getting word out, workers' time, & convincing workers & administrators that Assoc. is needed & can add value.

Appendix 3 ■ Maine PASA Project Worker Association Reference Information

State	Missouri (<i>national association</i>)	Michigan
Contact	Tom Guidry, Dir. 2709 W. 13 th St. Joplin, MO 64801 E-mail: Tguidry@magna.org Tel: (417) 623-6049 or (800) 784-6049 Fax: (417) 623-2230 http://www.magna.org & www.cnatoday.com	Kathy Flowers 8072 Kensington #211 Davison, MI 48423 Tel: (810) 742-1800 List Serv: http://www.Michigan-DSP@egroups.com
Official Name	National Assoc. of Geriatric Nursing Asssts.	Michigan Alliance of Direct Support Professionals
Founded	1995	2000
Description	National Assoc.	Open to anyone who supports their mission, goals, & activities.
Status	NP	Does not have NP status.
Mission, Vision & Values	Mission: To elevate the professional standing & performance of CNAs through recognition, advocacy, education, & empowerment while building a stronger alliance with health care providers to maximize success & quality of patient care. Vision: CNAs providing the highest level of care within their scope & responsibility, CNAs are recognized as professionals, CNAs serve as mentors for new nursing asssts., & honor & recognition for CNAs.	Michigan Alliance of Direct Support Professionals is a network of people committed to strengthening the quality of human services by empowering ourselves to increase our own dignity & respect.
Goals		To enhance the status of direct support professionals in Michigan.
Leadership Structure	CEO/Pres. & a CFO. Established board (<i>CNAs & health-care professionals</i>)	
Is Staff Paid?	No	No
Board Mtgs.	Qrtly.	
Activities & Printed Materials	Recognition, education, professional development, & consulting. Qrtly. magazine "CNA Today."	Provides community outreach & information about their work, promotes access to quality education in the field, & advocates for better wages, benefits, retirement, & job security.
Area Covered	Whole country.	State
Operations & Budget	Financial support is membership-based (<i>individual members & health care facilities</i>)	No fees.
Membership	22,000 CNAs	10 active members. 200-300 names on the mail list.
Challenges to Getting Started		Fear of union. Getting word to workers. Keeping a level of interest.

Appendix 3 ■ Maine PASA Project Worker Association Reference Information

State	New York	North Carolina
Contact	Not an active group.	Jan Moxley NC DHHS 2001 Mail Service Center Raleigh, NC 27699-2001 E-mail: jan.moxley@ncmail.net Tel: (919) 715-0807 Fax: (919) 733-7447
Official Name	New York State Certified Caregivers Assoc.	Direct Care Workers Assoc. of North Carolina
Founded	2001, then halted operations due to lack of funding.	May 2002
Description		
Status		Articles of Inc. filed April 2003 & bylaws adopted. Preparing for 501(c) 3 status.
Mission, Vision & Values		Mission: To improve the quality of care by promoting the interests of direct care workers through education, professional development, & public awareness. Vision: The state maintains a diverse & stable pool of dedicated, high-quality direct care workers that fully meets the needs of the people in North Carolina. The health care system in particular, & society as a whole, deeply value the roles direct care workers play as respected members of the health care team. Direct care workers have professional status & the opportunities for training, career growth, compensation, job benefits, & realistic workloads. Public policy makers will expect to receive meaningful input from direct care workers on issues that could affect their profession & the care they provide. Direct care professionals continuously strive to improve the care they provide to maximize the quality of life for people they serve.
Goals	Boost pride & future of excellence for certified caregivers. Raise quality of care.	
Leadership Structure		Board of Dirrs. with Pres., VP, Secretary, & Treasurer. 8-15 on Board (<i>2/3 workers, 1 consumer, & professionals</i>).
Is Staff Paid?		Travel expenses.
Board Mtgs.		Monthly
Activities & Printed Materials	Workshops, newsletters, & building mailing list.	Brochure with mail-in registration, membership drive, collaboration with AAA, sign-up programs at conferences & workshops, support education, peer support, & networking. Mailing list is statewide.
Area Covered		Statewide
Operations & Budget	No membership dues.	Membership dues are a small source. Seeking grants & fund-raisers. "Real Choice" grant now.
Membership		
Challenges to Getting Started	Ran out of money & there are no plans to try again.	

Appendix 3 ■ Maine PASA Project Worker Association Reference Information

State	Virginia	Wisconsin
Contact	Lorrene Maynard, CNA, Dir. VA Assoc. for Prof. Nursing Assts., Inc. P.O. Box 3732 Hampton, VA 23663 Tel: (757) 265-8307 E-mail: professionalcna@aol.com	
Official Name	Virginia Assoc. of Professional Nursing Assts.	Wisconsin Caregivers Assoc.
Founded	March 1997	1999
Description	Assoc. for Home Health Aides & CNAs are members of a larger group.	
Status	NP	
Mission, Vision & Values	Mission: To promote quality care in all healthcare settings where CNAs are employed, to promote the professionalism & development of nursing assts. in the state of Virginia, & to allow nursing assts. a legislative platform by networking with other CNA groups.	
Goals	Bridge gaps in health care settings & educating the community at large.	Promote dignity of care workers.
Leadership Structure	Pres., VP, Secretary, Treasurer (<i>all CNAs according to by-laws</i>), & advisory council (<i>LPNs</i>).	
Is Staff Paid?	No	
Board Mtgs.	Qrtly.	
Activities & Printed Materials	Newsletter & brochure to outreach & network, peer support, voter registration drives, & discounts for uniforms.	Workshops, newsletter, & awards.
Area Covered		
Operations & Budget	Member-supported	Membership dues: \$15/worker, \$25/professional, & \$100/agency.
Membership	20 CNAs & 3 licensed professionals.	250 Members.
Challenges to Getting Started	Funding, etc.	Fear of union. Getting workers' involvement.

Appendix 3 ■ Maine PASA Project Worker Association Reference Information

State	National Alliance for Direct Support Professionals
Contact	www.NADSP.org
Official Name	National Alliance for Direct Support Professionals
Founded	
Description	NADSP is a coalition of organizations & individuals committed to strengthening the quality of human service support by strengthening the direct support workforce. The group has representatives from the fields of mental health, dev. disabilities, child welfare, education, & many others in the human services community.
Status	
Mission, Vision & Values	Mission: The NADSP's mission is to promote the development of a highly-competent human services workforce that supports individuals in achieving their life goals. Vision: The NADSP believes that service participants & direct support professionals are partners in the move towards a self-determined life, & in complementing & facilitating growth of natural supports. We recognize that people needing support are more likely to fulfill their life dreams if they have well-trained, experienced, & motivated people at their side in long-term, stable, & compatible support relationships. We also recognize that well-planned workforce development strategies are needed to strengthen our workforce.
Goals	1. Enhance the status of direct support professionals. 2. Provide better access for all direct support professionals to high-quality educational experiences (e.g., <i>in-service training & continuing & higher education</i>) & lifelong learning which enhances competency. 3. Strengthening the working relationships & partnerships between direct support professionals, self-advocates, other consumer groups, & families. 4. Promote systems reform which provides incentives for educational experiences, increased compensation, & access to career pathways for direct support professionals through the promotion of policy initiatives (e.g., <i>legislation, funding, & practices</i>). 5. Support the development & implementation of a national volunteer credentialing process for direct support professionals.
Leadership Structure	
Is Staff Paid?	
Board Mtgs.	
Activities & Printed Materials	
Area Covered	
Operations & Budget	
Membership	
Challenges to Getting Started	

FOR IMMEDIATE RELEASE

October 18, 2002

Contact: Elise Scala
207-228-8423

PERSONAL ASSISTANCE SERVICES ASSOCIATION LAUNCHED IN MAINE

Portland, ME—The Edmund S. Muskie School of Public Service at the University of Southern Maine is hosting a free breakfast event to recognize personal assistance and direct care workers and to support the development of a new professional association. The breakfast will be held Saturday, October 26th at Lewiston-Auburn College in Lewiston. For more information and to register, call toll free 1-800-268-6612, (TTY 207-228-8440) or e-mail scala@usm.maine.edu.

“Direct care work, including personal care and home health aides, is the seventh fastest growing occupation in the nation, and Maine, like many other states, has a shortage of workers,” explains Elise Scala, Project Coordinator. “Associations are being developed in many states to support, train and retain workers in assistant and caregiver jobs and this grant funded project will support the development of an association in Maine.”

The Maine Personal Assistance Services Association project is part of the Real Choices Grant awarded to Maine by the federal Centers for Medicaid & Medicare Services to support the improvement of home and community-based resources and services for persons with disabilities. The grant partners, the Maine Bureau of Medical Services, Maine’s Plan Development Work Group for Community Based Living and the Muskie School of Public Service at the University of Southern Maine, are pleased to announce this event to recognize personal assistance service workers and to launch the Maine Personal Assistance Services Association.

Program Evaluation 2003 Forum

Please, let us know how we did.

The Program

1. The program gave me useful information: Yes No
2. The speaker: Made me think. Was hard to understand.
- | | |
|--|--------------------------|
| <input type="checkbox"/> Chris Gianopoulos | <input type="checkbox"/> |
| <input type="checkbox"/> Linda Mills | <input type="checkbox"/> |
| <input type="checkbox"/> Betty Hill | <input type="checkbox"/> |
| <input type="checkbox"/> Di Findley | <input type="checkbox"/> |
3. The small group discussion: (Check as many as you want.)
- Helped me appreciate personal assistance work.
 - I would have liked more time to talk with others.
 - I really wanted to talk about _____
4. The large group discussion:
- Helped me understand what an association could do in Maine.
 - Showed that an association is not needed.
5. I wish there had been time to _____
(Please fill in the end of the sentence.)
6. The plan for an association in Maine:
- Sounds good
 - Is not for me
 - Worries me (Why? _____)

The Location

- Lewiston was: Convenient Inconvenient
- The College was: Easy to find Hard to find

The Facility

- The room was: Comfortable Uncomfortable

I would have liked _____
(Please finish this sentence and let us know how it can be improved.)

The Food

- The food was: Excellent Good Poor

Questionnaire Source: USM, Muskie School. Contact: Elise Scala, scala@usm.maine.edu or (207) 228-8423.
(9/02)

The program coordinators for an Association in Maine would like to hear from you. The information from questionnaires will be used to:

- develop a mailing list to inform people of Association activities;
- identify people who are interested in helping to develop the Association; and
- collect information on what people want an Association to provide for its members. (All individual answers will be kept private and confidential).

1. Your job title: _____
2. Your employer: (Check all that apply.)
 - Home Health Agency
 - Nursing Home
 - Hospital
 - Residential Care (boarding home or assisted living)
 - Consumer Directed Waiver
 - Privately Hired
 - Other: _____
3. Your work schedule:
 - Part-time for one employer (____ hours/week)
 - Full-time for one employer
 - More than one job. Please describe _____
4. What would you like an Association to do for you? (Check all that apply.)
 - Provide a time and place to meet and talk to other people who do similar work.
 - Offer programs for work related training (skills classes, certification program).
 - Offer programs for personal development (managing money, stress, etc.).
 - Provide career information and referral services.
 - Provide health insurance benefits.
 - Provide a certificate of membership to show association credentials.
 - Build public awareness of the value of assistant and aide work.
 - Build support for improved wages and benefits.
 - Tell us what else you would like: _____
5. Do you think Maine needs an Association to support personal assistants and others who work in direct care and aide jobs? Yes No
6. Do groups, like an association, already exist in Maine to provide support to personal assistance services workers? Yes No
If you answered yes, please tell us who they are so we can coordinate with them: _____
7. If you are interested in a Maine Personal Assistance Services Association, please provide the following information:
 - Yes, I would be interested in joining the Association.
 - Yes, I am interested in being on an association committee in my area.

Name: _____

Address: _____

Email: _____

Questionnaire Source: *USM, Muskie School. Contact: Elise Scala, scala@usm.maine.edu or (207) 228-8423.*
(9/02)

Maine Personal Assistance Services Association
Outcomes: Breakfast Event, October 26, 2002 Questionnaire

Event Attendance

Registrations: 62
 Attendees: 49

Results

Total number of completed questionnaires: 39 (80%)
 Number completed by personal assistance workers: 31 (8 indicated positions in management, education or RNs)

Questionnaires Completed by Workers

<u>Job Titles:</u>	<u>Employer:</u>
Direct Care Workers: 5 (16%)	Home Health: 10 (33%)
Behavioral Spec: 1 (3%)	Nursing Home: 3 (10%)
PCA: 15 (48%)	Res. Care: 7 (23%)
CNA: 6 (19%)	Private Hire: 5 (17%)
Coach/ Res. Asst.: 2 (6%)	Consumer Directed: 1 (3%)
? (not completed) 2 (6%)	Other: 3 (10%)
	(Skilled Unit, AlphaOne, Comm. For-Profit MH)

Work Status:

Full Time: 17 (65%)
 Part Time: 4 (15%)
 More than 1 job: 5 (19%)
 Student:

Does Maine need an association to support personal assistants and others who work in direct care and aide jobs?
 YES: 30 (97%) NO: 1 (3%)

Do groups, like an association already exist in Maine?
 (Two were identified: Union and the National Association of Direct Care Professionals)
 YES: 2 NO: 21

What would you like an association to do for you?

- 24 ☺ Build support for improved wages and benefits.
- 21 ☺ Build public awareness of the value of assistant and aide work.
- 20 ☺ Offer programs for work related training (skills classes, certification program).
- 19 ☺ Provide career information and referral services.
- 18 ☺ Provide a time and place to meet and talk to other people who do similar work.
- 15 ☺ Provide health insurance benefits.
- 15 ☺ Provide a certificate of membership to show association credentials.
- 9 ☺ Offer programs for personal development (managing money, stress, etc.).
- 3 ☺ Other: Self advocacy, protection, injury prevention.

Interest in Participation:

- 25 ☺ Yes, I am interested in joining the association.
- 9 ☺ Yes, I am interested in being on an association committee.



November 14, 2003 Event Questionnaire Results

Event Attendance

Registrations: 36

Attendees: 59 (number includes registrants, staff, and presenters)

Results

Total number of completed questionnaires: 28

1. Overall, the program gave me useful info.

Yes: 27

No: 0

Did not answer: 1

2. Overall, I give the program a rating of:

Poor: 0

Pretty Good: 2

Really Good, I will come again: 25

Did not answer: 1

3. The Speakers... made me think were hard to understand

Patsy Harris 25 2

Cathy Ludlum 27 0

Ed Latham 24 0

Difference made up by some who did not answer or did not attend.

Comments:

- "All inspiring in their own separate ways"
- "Ed was a wonderful speaker. You got to love the guy."
- "Excellent, all."
- "Great spirit of caregiving"
- "Patsy didn't seem able to finish a thought without starting a new one."
- "Re: class with Ed Latham... You should let us know we need to wear Depends."
- "They were wonderful."
- "Very good! Really enjoyed it!"
- "What a good day! Thanks!"
- "Wonderful presenters"
- "Wonderful, inspiring speakers"

4. The Panel Discussion...

25 helped me understand what an Association can do in Maine

25 demonstrated how valuable an Association can be for workers.

20 makes me glad I am a member of Maine PASA, or I want to join.

Comments:

- "As a founding member of the Association, you have a voice, use it."
- "Didn't attend."
- "I am a member."
- "I felt appreciated, supported, respected. It was really great!"
- "I would love to help in any way I can."
- "Mixed feelings - only experienced in this field for 3 months."
- "Thank you for establishing a great network for us."

Read on for more results ➔

5. The Program Schedule

Length of the program:

Full day was good

Yes: 22

Difference made up by some who did not answer or did not attend.

Would have preferred:

- “9a-3p”
- “half day” (2)
- “Less registration and opening remarks time.”
- “Long, but valuable”

Variety:

I liked the choices of speakers and workshops.

Yes: 24

Difference made up by some who did not answer or did not attend.

Workshops:

Good selection of topics: 20

Difference made up by some who did not answer or did not attend.

I would have liked to have seen:

- “CNA participation”
- “Ed [assuming they mean Ed Latham]”
- “hands-on demonstrations, searches, etc.”
- “personal empowerment”
- “Structured ‘meet each other’ time”

Too many, not enough time: 2

Difference made up by some who did not answer or did not attend.

Comments:

- “Difficult to choose”
- “Difficult to make choice. All the workshops were helpful, well-thought and encouraging.”
- “Excellent”
- “I liked the choices. Would have liked to have heard them all.”
- “Like to see workshops longer, if possible. Would like to see workshops taped to be able to share them.”
- “Longer times for the workshops”
- “More on what we can do politically to gain benefits.”
- “Would like to have participated in all workshops. A great experience for me and a wealth of information.”

6. The Date

The Friday/weekday was best: 22

Saturday preferred: 2

Did not answer: 4

7. The Location

Convenient: 23

Inconvenient: 2

Did not answer: 3

Suggestions for next year:

- “Augusta”
- “Augusta Civic Center”
- “Closer to the coast”
- “Lewiston, Lewiston, Lewiston”
- “OK. Traveled 1.5 hours by car to get here.”
- “Portland area”
- “Same”
- “York county”

8. The Facility

Comfortable: 25

Uncomfortable: 2

Did not answer: 1

Suggestions for improvements:

- “A little cold in the morning.”
- “It was a little cold.”
- “It was slightly cool.”
- “Main room was very cold.”
- “Put resource tables in main conference room instead of out in the hallway.”
- “Rooms closer together”
- “Very cold”
- “Was cold.”

9. The Food

Poor: 0

Good: 14

Great: 11

Did not answer: 3

Requests for next time:

- “Best food I’ve had yet!”
- “Salad bar”
- “Would prefer 2 selections of soups. Great sandwiches.”

Maine Direct Care Worker Coalition

Mission

To promote policy and practices that respect and value direct care workers in order to sustain quality direct care in Maine.

Introduction

Since June 2002, representatives from long-term care providers, labor organizations, and advocacy groups have met regularly to address compensation and other issues for direct care workers in Maine's long-term care system. Participants crafted a set of guiding principles, which have been endorsed by a number of organizations. This process has created the Direct Care Worker Coalition. "Signing-on" to the coalition indicates agreement with the principles and agreement to explore policy solutions that advance the principles. Signing on does not commit any organization to endorse particular legislation nor does it mean that these organizations endorse the activities of other member groups.

If and when the coalition develops a legislative proposal or activity, every coalition partner will be asked again to consider supporting such legislation or activity through their normal organizational decision making channels. All documents and releases about coalition activities will reflect only those organizations endorsing the joint activities agreed to at that time. Neither the Principles nor legislation will be described as a coalition document until either:

1. All those organizations previously adhering to the principles have agreed to support the legislation, or
2. At a full coalition meeting a majority of groups decide to change the definition of coalition membership to limit the coalition to those groups supporting such a legislative draft.

Principles

The Direct Care Worker Coalition is dedicated to quality long-term health care services in Maine. Quality services are best guaranteed through a coordinated health care system with trained and adequate staffing at all levels.

Front line, direct care workers play a crucial role in providing quality health care services. These workers include those working for institutions and those working independently for consumers. A critical component to the provision of timely, individualized quality care is an adequate level of consistent care giving staff. Adequate, qualified staffing is maintained when the entire health care system values, supports, and compensates direct caregivers.

Maine faces a critical shortage of direct care workers in the long-term care system due to a combination of a tight labor market and a wage level limited by current Medicare and Medicaid rates. This problem exists throughout the long-term care system and is only going to worsen as impending demographic changes increase the aging population and decrease the labor pool.

The Direct Care Worker Coalition seeks to reverse this trend and ensure the quality of care, quality of life, health and safety of long term care consumers by better ensuring a system that attracts and retains direct caregivers.

The Coalition is committed to representation from all related sectors and its members include long-term care managers from nursing homes, assisted living/residential care facilities, and home care agencies; consumers, consumer representatives, direct care workers, labor, businesses, and policy makers.

The Coalition is organized around the following principles:

High quality long-term health care services require:

- A humane, holistic, and consumer-centered approach to care.
- Adequate, qualified and valued staff at all levels.
- Direct care workers’ right to advocate effectively for consumers and themselves.
- Continuity of consumer care.

Long-term health care service organizations must be given adequate reimbursements to support:

- A safe environment for staff and consumers.
- Adequate compensation to meet the basic needs of workers.
- Job flexibility, benefits, and advancement opportunities for workers.
- Seamless, available staff training in an atmosphere of ongoing learning.

Members as of 2004:

- | | |
|---|--|
| <ol style="list-style-type: none"> 1. Catholic Diocese of Maine 2. Coastal Enterprises, Inc. 3. Consumers for Affordable Health Care 4. Home Care Alliance of Maine 5. Home Care for ME 6. Maine Alzheimer’s Association 7. Maine AFL/CIO 8. Maine Association of Interdependent Neighborhoods 9. Maine Center for Economic Policy 10. Maine Council of Churches 11. Maine Health Care Association 12. Maine Long Term Care Ombudsman 13. Maine Nurse Practitioner Association | <ol style="list-style-type: none"> 14. Maine Personal Assistance Services Association 15. Maine Rural Health Association 16. MSEA/SEIU 17. Maine State Nurses Association 18. Medical Care Development 19. National Council on Aging 20. Northern New England Association for Housing and Services for the Aging 21. PCA Provider Network 22. Sandy River Health Resources 23. Sarah Frye Home 24. University of Maine Center on Aging 25. Maine Women’s Policy Center |
|---|--|

For more information contact:

Lisa Pohlmann, Associate Director
 Maine Center for Economic Policy
 P.O. Box 437
 Augusta, ME 04332
 207-622-7381
 lpohlmann@mecep.org

Maine PASA Accomplishments (Fall 2002 - Spring 2004)

- 2 annual conferences, for members and member recruiting, offering networking and support with topics for professional and personal growth presented by recognized state and national speakers.
- Newsletters: 8 bi-monthly editions published
- Distribution mailing list of nearly 450
- Name recognition developed
- Logo designed, brochure published, 5,000 distributed
- PO Box, toll free phone line receiving a continuous trickle of inquiries
- Website URL in place: www.mainepasa.org (site under construction)
- Monthly meetings for over a year with a core group of dedicated direct support professional and direct care workers who have engaged, taken on new responsibilities and grown with the opportunity to build Maine PASA
- State recognition: Invited to serve on two major committees: Direct Care Worker Coalition and the Maine Joint Advisory Council
- Formally recognized by the Eastern Maine Chapter of the National Gerontological Nursing Association
- National recognition: listed on the Direct Care Clearinghouse website as one of the associations in the country, links with the Direct Care Alliance.
- Well connected nationally: grant work with the federal Centers for Medicare and Medicaid Services, Robert Wood Johnson Foundation's Better Jobs Better Care Programs
- Co-founder of the New England Coalition of Worker Association and Advocacy Projects and serves as mentor and mentee with other state based associations
- Presentations at national conference and state conferences, to agency boards, staff groups, job fair, and the Maine Legislature
- Press: Newspaper articles and feature stories in national newsletters and websites.
- 2nd federal grant awarded to the State that includes funds to support Maine PASA operations, part time manager and development of the website

List compiled May 2004

Maine PASA 501(c)(3) Application

PART II Activities and Operational Information

1. Description of organization activities

Background

The Maine Personal Assistance Services Association, Maine PASA, was established through a grant awarded to the State of Maine by the Federal Centers for Medicare & Medicaid Services Real Choices Systems Change Grant. The grant provided limited assistance to develop the Association with the intent for the organization to be fully developed and self-sustaining by the end of the grant in 2004.

Planned and Initiated Activities (In order of Importance)

1. Serve as a statewide coordinator of programs to promote quality direct care and direct support work

Time proposed for activity: 40%

Description & Purpose: The following activities have been and will be conducted to accomplish the organizational mission to build recognition for direct care/support and personal assistant work through education and public awareness:

- Conduct outreach programs and activities for direct care/direct support/personal assistants and their employers to inform them of Maine PASA programs, state wide events and state and national information relevant to long term care and the direct care/support workforce.
- Conduct programs and activities to raise public awareness about the importance of the front line/direct care and support workforce and the importance of quality in long term care for elders and people with disabilities
- Coordinate professional development programs and information for the direct care/support and personal assistance workforce and for current and prospective Maine PASA members.

Activity Planned: Maine PASA meetings are scheduled for Fall 2004 for regional programs in Bangor, Augusta, mid-coast and Southern Maine. Longer range programs have been funded through grants and contracts for programs and member activities through September 2006.

Activity Conducted: Statewide annual events have been conducted by Maine PASA in the fall of 2002, 2003. The third event in September 2004 involved co-sponsoring a large conference, “Excellence in Long Term Care, with the Maine Health Care Association, Home Care Alliance of Maine and the Maine Long Term Care Ombudsman Program. Since 2002 Maine PASA has held and/or been a contributor to numerous local, regional, state and national programs, employer meetings and conference presentations, state meetings and national conferences. (See attached Appendix 1)

Activity Location: Maine PASA programs have been conducted in multiple locations in Maine ranging from Bangor and south. Members are located statewide and future program will extend to north and western regions of Maine.

Activity Conducted By: Maine PASA has been developed by staff at the Muskie School, University of Southern Maine with input from direct care/support members and other members and stakeholders in the state and general public.

2. Serve as a statewide source of public information about direct care/support work and workers in long term care and support.

Time proposed for activity: 40%

Description & Purpose: The following activities will involve the collection and dissemination of information to raise awareness and inform members and stakeholders in long term care services. These activities are intended to help recruit and retain people in these jobs.

- Bi-monthly newsletter
 - Website
 - Worker listing project for consumers and employers
 - Submissions to local, state, other state and national publications and websites.
 - Presentations at local, state, other state and national programs, conferences, events.
- Activity Planned:** Publication of the Maine PASA newsletter and website will continue. The Worker Listing feature is being designed for January 2005 operations. The Our Stories project, currently on the website and featured in installments in the newsletter will be developed for print publication in 2005.

Activity Conducted: Newsletters produced (8) Nov 02, Feb 03, April 03, June 03, Aug 03, Nov 03, Feb 04, April 04, Aug 04; Website (www.maine-pasa.org); Our Stories Project was launched in Summer 2004 and will be added to through Fall 2004.

Activity Location: The newsletter and website has been generated from the Muskie School, University of Southern Maine, located in Portland, Maine, with input from Maine PASA members statewide.

Conducted By: The project coordinator and support staff at the Muskie School with input from Maine PASA members.

3. Serve on state and national initiatives focused on direct care and support workforce development

Time proposed for activity: 10%

Description & Purpose: The following activities will provide the opportunities for direct care and support members to participate in state sponsored groups and national programs to address the policies and challenges in long term care and support services. Participating members will have the opportunity to build their leadership and communications skills and to learn about the policies and practices of long term care.

- Members attend state committee meetings, participate in discussions and write articles for the newsletter to inform others in the State.
- Members attend national conferences as presenters and participants from Maine.
- Identify work groups and state committees that will need members of the workforce to contribute to discussions on events, issues, best practices, quality and systems change.

Activity Planned: Maine PASA receives regular invitations to participate in meetings and to serve on committees and to be included in state and federal grant programs to address recruitment and retention needs for direct care/support and personal assistants. The activities detailed as ‘conducted’, below, are expected to continue.

Activity Conducted: Maine PASA members are currently servicing on the following workgroups: The Maine Direct Care Worker Coalition, a multi-stakeholder group the is addressing workforce questions for the Maine Legislature; Maine’s Consumer Directed Personal Assistance Services, CD-PAS Workgroup, Maine Joint Advisory Council MeJAC, to address the needs for policies and programs to service adults with dementia and violent behavior. National programs that have featured Maine PASA include the Milwaukee Home to Community Based Services Conference (Fall 2003), Centers for Medicaid & Medicare Services Annual Program

(Spring 2004), National Conference of the Direct Care Workers Alliance Fall 2004 (see attachment Appendix 2).

Activity Location: State based meetings are located in Portland and Augusta, Maine. National conferences are generally held in Washington and Baltimore.

Activity Conducted By: The project coordinator and/or Maine PASA members attend the meetings which are held by State administrators and members of other Maine based organizations or a sponsoring organization affiliated with the federal grant funders.

4. Maine PASA Organizational Development

Time proposed for activity: 10%

Description & Purpose: The following activities will develop and operate Maine PASA to be a competent and responsible non-profit organization for the state of Maine and the Nation.

- To hold regular meetings of the Board of Directors organized by elected officers.
- To employ an executive director and support staff.
- To form committees of Board members and Maine PASA members to focus on key activities and to report to the full Board. These will include the Business Committee, Program Committee, Development Committee, Communications Committee.
- To complete annual reports and conduct meetings to inform the full membership and public of Maine PASA activities and accomplishments and to conduct an annual assessment process.
- Continuous examination by Board members to assess Maine PASA efforts to respond to training and development needs and to respond to public education issues pertaining to direct care and support workforce and quality of care issues.

Activity Planned: Monthly board meetings will continue for the next 6 months to manage the development phase of the organization. Upcoming events include the recruitment and appointment of an executive director, relocation to a new office location and other transitions for shifting Maine PASA from a grant-based project to a self-supporting non-profit with a statewide membership. The number of local chapters will increase to provide locally-located programs to maximize accessibility for members. Member development will continue and strategic planning for fund development will be initiated.

Activity Conducted: Maine PASA established a core group of founding members in the Winter of 2003 and have been meeting monthly for nearly two years. The Founding Member group has transitioned to be the Board of Directors. Regular monthly meetings and a retreat has produced a revised mission statement and bylaws. The Board made its first public debut by hosting a reception at the annual event on September 27th, 2004.

Activity Location: The base of operation has been in Portland Maine, with the project coordinator. Meetings of the Board of being held in Farmingdale.

Activity Conducted By: Coordination has been completed by the Project Coordinator through the Muskie School with leadership from the Board officers and general board. The Board is poised for transfer to a to-be-hired executive director. (Attachment, Appendix #4: Board of Directors, Member list)

2. Sources of Financial Support

- 1. Primary Sources:** For the period September 2002 – September 2006 grant funds have been the primary source of financial support for Maine PASA (federal grants to State of Maine, Cooperative Agreement to University of Southern Maine Muskie School of Public Service and subcontracted to Maine PASA). New proposals have been submitted to secure additional federal grant funds and future proposals to federal, state and private foundations is planned.
- 2. Minor Sources:** Registrations to Maine PASA events, donations for Maine PASA events for materials and member attendance, and the in-kind contributions of members and benefactors for operational support, program meeting sites and materials. A future option to require a nominal membership dues will be considered by the Board but no plans have been identified at this time.

3. Fundraising Activities

- 1. Current Fundraising Activities:** None at the present time
- 2. Planned Fundraising Activities:** There are no plans currently in effect. The Board of Directors will assess the need and strategic plans for fundraising in the future. While no plans have been put into effect to solicit funds Maine PASA is expected to attract contributions from members and the public in recognition of its mission. Procedures for accepting these contributions and recognizing their use for operations and member participation in educational programs will be developed.

Maine Personal Assistance Services Association Bylaws Document 2005

ARTICLE I - NAME, PURPOSE

Section 1 – Name: The name of the organization is Maine Personal Assistance Services Association.

Section 2 – Purpose: The Maine Personal Assistance Services Association is organized exclusively for charitable, educational and scientific purposes. The purposes of Maine Personal Assistance Services Association are :

- To form a coalition consisting of diverse members of the personal assistance and direct care and support workforce and to develop and articulate a common mission;
- To empower members by providing a place to share common goals for quality care and human dignity, respect for consumer choice and a voice that promotes the value of the work and workers;
- To provide opportunities for members to network, and to gain knowledge and skills necessary to further personal and professional goals;
- To promote community efforts at enhancing and improving work environments for members;
- To improve the quality of jobs by promoting the recognition of workers and the value of their work as a profession based on caring and quality.

ARTICLE II - MEMBERSHIP

Section 1 - Eligibility for membership: There shall be two classes of members: Primary Members and Support Members.

- a) Primary Members. Any worker employed in Maine to provide personal assistance, direct care, or direct support, regardless of job title, certification and place of employment may become a Primary Member. This category of membership is also available to personal care workers who are not currently in the workforce, to retired workers, and to certain students in programs related to providing personal care. Primary Membership is granted after completion and receipt of a membership application. Determination of the Primary Members shall be made by the Board of Directors or by Association Staff, as directed by the Board. Primary Members have a right to vote at the Association meetings or vote by mail.
- b) Support Members. Any individual or organization that supports the purpose statement in Article I, Section 2 and is willing to contribute to the Maine Personal Assistance Services Association's goals and activities shall be eligible to become a Support Member. Support membership is granted after completion and receipt of a membership application by the staff of the Association.

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Section 2 – Annual dues: Membership dues are determined by the Board of Directors and are payable by January 31 of each year. There are no membership dues at this time.

Section 3 – Refusal of membership: Maine PASA reserves the right to refuse primary or support membership to any individuals and organizations, provided the refusal does not violate State or Federal law.

Section 4 – Benefits and rights of members:

- a) All individual members will receive a personal primary or support membership card. Organization members will receive a certificate of membership their first year and a certificate of renewal in subsequent years of membership.
- b) All members will receive a copy of the Association’s newsletter and notification of programs and functions. All current and registered Primary Members will have a right to vote on any matters brought to the Association’s meeting, in person or by mail.

Section 5 – Termination of membership: A membership of either classification shall terminate upon any one of the following:

- a) A written or oral statement of resignation by the member given to Secretary.
- b) Non-payment of dues after 30 days of one mailed notification for membership renewal.
- c) Conduct deemed detrimental to the Association. Such action will take a two-thirds (2/3) vote of the Board of Directors present and voting.

ARTICLE III- CHAPTERS

The Association may create one or more local Chapters. Members of each Chapter shall be members of this Association in the same manner as described herein. The Board of Directors shall establish chapters and their operating procedures. Each Chapter may meet at such times as it may deem appropriate. Any and all activities undertaken by a Chapter must be consistent with the purposes of this Association. The Chapters will be responsible for maintaining communications with the Executive Director. Each chapter will report on its activities at the Annual Meeting of the Association.

ARTICLE IV - MEETINGS

Section 1 - Annual meetings: The date of the annual meeting of the Association shall be on the first Monday in June of each year or on a date, time and place set by the Board of Directors. At the annual meeting the membership will receive reports on the activities of the Association and will conduct such other business as may come before the membership, as described in these By-Laws

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Section 2 - Other or Special Meetings: The Board of Directors, the Chair, or the Executive Committee may call other or special meetings of the membership provided that Notice is provided as in Section 4.

Section 3 – Mail: The Association, through its Board of Directors, may ask members to vote on a matter by mail. In such a case, the Association will send a ballot to each registered member entitled to vote at least 15 days prior to a deadline set for receiving the ballots.

Section 4 – Notice: Notice of each meeting shall be given to each member, by mail or electronic mail, not less than ten days before the meeting.

Section 5 – Quorum: The members present at any properly announced meeting of the Association shall constitute a quorum. Article V, Section 12 defines the Quorum for Board business meetings to be ½ of members.

Section 6 – Voting: All issues to be voted on shall be decided by a simple majority of those present at the meeting in which the vote takes place, or by mail, returned within the posted deadline.

ARTICLE V - BOARD OF DIRECTORS

Section 1 - Board Size and Compensation: The Governance of the Association shall be conducted by the Board of Directors. The Board of Directors is responsible for overall policy and direction of the Association. The Board delegates responsibility for day-to-day operations to, Staff, Directors and committees. The Board shall consist of up to 15 members, but not fewer than 5 members, all of whom are Primary or Support Members of the Association. The number of support members on the Board shall not exceed one half of current sitting Board members. Members of the board shall not receive compensation for services, other than reimbursement for reasonable business-related expenses.

Section 2 – Duties of the Board: The duties of the Board of Directors are to:

1. Regularly review the Association's mission and purpose.
2. Employ and evaluate the Executive Director.
3. Support the Chair and review his or her performance.
4. Ensure effective organizational planning.
5. Ensure adequate resources.
6. Review space needs and provide for the space and materials necessary to run the Association's office.
7. Manage resources effectively, including the adoption and review of annual budgets
8. Determine and monitor the Association's programs and services.
9. Enhance the Association's public image.

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10. Assess the Board's own performance.
11. Identify the need for the Advisory Board and appoint the Advisory Board members.
12. Development activities, including grant-writing, identification of financial sources, and fundraising activities.
13. Board Development, including identification and recruitment of potential new board members.

Section 3 – Meetings: The Board shall meet at least bimonthly, at an agreed upon time and place.

Section 4 - Agenda: The Chair or Secretary shall, prior to the commencement of the meeting, provide an Agenda of items to be discussed or acted upon at the meeting. At a minimum, the Agenda shall contain the following items:

1. Record Attendance of those present.
2. Approval of minutes of previous meeting.
Treasurer's Report.
3. Reports of Committees or Subcommittees.
4. Old Business.
5. New Business.
6. Set time for next meeting
7. Adjourn

Section 5 - Rules: All proceedings of the Board shall be governed by Roberts Rules of Order. The Chair shall have all authority over all proceedings.

Section 6 - Board Elections: Election of new officers to the Board of Directors or election of current officers to a second term will occur as the first item of business at the time of the annual meeting of the corporation. Board officers will be elected by a majority vote of the current Board Members with the approval of the membership of the Association. The ultimate determination of membership on the Board shall be the responsibility of the Board itself.

Section 7 - Resignation, Termination and Absences: Resignation from the Board must be in writing and received by the Secretary. A Board member shall be terminated for excess absences from the Board if s/he has three consecutive absences from the Board meetings without notifying the Secretary. A Board member may be removed for other reasons by a three-fourths vote of the remaining directors.

Section 8 - Nominations: A call for nominations for Board members shall be sent to all Maine PASA members, through the newsletter or an individual mailing. Nominations will be received by the Board of Directors on or before

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a due date established by the Board. Nominees shall be individual primary or support members of the Association.

Section 9 – Nominating Committee: The Nominating Committee of the Board will consider Nominees. The Committee may consist of the entire Board or not less than three members of the Board. New Members to the Board will be elected by a majority vote of the Board members present and voting at the meeting.

Section 10 – Vacancies: Vacancies on the Board, due to resignation and or to a seat being declared vacant, may be filled by a simple majority vote of the Board of Directors present and voting at the meeting of the Board. These vacancies will be filled according to Primary or Support positions and only to the end of the particular Board member's term.

Section 11 – Terms: The term of all Board members shall be for two-years, unless the Board indicates in advance that a position will have one-year term. All Board Members are eligible for re-election to a two-year term. No person shall be eligible to serve more than three (3) consecutive two-year terms.

Section 12 – Quorum: At least one half (1/2) of qualified Board members must be present before the commencement of a business meeting in order to constitute a quorum for the transaction of any business of the Board of Directors. The quorum will remain effective for the date of the meeting, even if some Board Members are not present for the entire meeting.

Section 13 – Notice: Each Board member shall have written notice of meetings at least ten (10) days in advance of the meeting date

Section 14 – Special Meetings: Special meetings of the Board shall be called upon the request of the Chair or one-third of the Board. The Secretary shall send out notices of special meetings to each Board member ten (10) days in advance.

Section 15 – Meetings by Consent: Board members may, by unanimous consent of all Board Members, waive the notice provisions for a meeting and hold a meeting by consent, through written or electronic means. Board members may, if the Board approves, vote on issues before the Board by means of telephone.

ARTICLE VI– OFFICERS OF THE BOARD

Section 1 - Officers: There shall be four (4) officers of the Board: a Chair (or Co-chairs), Vice Chair, Secretary and Treasurer. No person may hold more than one position at the same time, except that the Board may, in its discretion, designate one or both Co-Chairs to act as Vice-Chair.

Maine PASA
EIN# 68-0585854

Section 2 – Duties of the Officers: The duties of the officers shall be as follows:

- a. The Chair, or Co-chair shall convene regularly scheduled Board meetings, and shall preside or arrange for other members of the executive committee to preside at each meeting in the following order: Vice-Chair, Secretary and Treasurer. The Chair, or Co-Chair, is the Chair of the Association as well as of the Board, and is authorized to act as “President” of the Association. In the event that the Board determines that two persons shall serve as Co-Chairs, each such person shall be vested with full administrative authority, but no action may be taken without the agreement of the other Co-chair. If the two Co-Chairs cannot agree on a matter, then the Board shall decide the matter, by majority vote of all active Board Members. The Chair, or Co-Chair, must be a “Primary” Member of the Association.

The Co-Chairs shall serve two-year terms on a staggered basis. Initially, one Co-Chair will serve a one-year term and one Co-Chair will serve a two-year term, establishing a “senior” and “trainee” position for the Chairs.
- b. The Vice-Chair may chair committees on special subjects as designated by the Board. A Co-Chair may act as a Vice-Chair.
- c. The Secretary shall be responsible for keeping records of Board actions, including taking minutes at all board meetings, sending out meeting announcements, distributing copies of minutes and the agenda to each Board member, and assuring that corporate records are maintained.
- d. The Treasurer shall make a report at each Board meeting. Treasurer shall chair the finance committee, assist in the preparation of the budget, help develop fundraising plans, and make financial information available to Board members and the public. The Treasurer shall be the Treasurer of the Corporation and shall have the duties and responsibilities of a Treasurer under Maine law.

Section 3 - Other officers: The Board may designate such other persons to fill temporary positions of officers as may be necessary; but no other officer positions may exist on a permanent basis unless these bylaws are amended.

Section 4 - Election of Officers: The Board shall, at its Annual Meeting, elect a Chair (or two Co-Chairs), a Vice Chair, a Secretary, and a Treasurer. Nominations for officers shall come from the Nominating Committee, and from the Board Members. Each officer shall serve a one-year term, except that Co-chairs shall serve two year terms on a staggered basis. Each officer may be re-elected to an additional one-year term; but no officer may serve in that position more than two consecutive one-year terms.

ARTICLE VII – ADVISORY BOARD

Maine PASA Bylaws: Reviewed March 2005

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EIN# 68-0585854

Section 1: The Board may, from time to time, appoint as Advisory Directors, persons whose advice, assistance and support may be deemed helpful in determining policies and formulating programs for carrying out the purposes of the Maine PASA and may fix reasonable reimbursable costs for attendance at meetings. The Board of Directors shall determine the term of office of each Advisory Director. The function of such Advisory Directors shall be to advise the Board with respect to all or any part of the affairs and/or operations of the Association as the Board may determine and designate in the appointment of such Advisory Directors. Advisory Directors shall be concerned about the needs of the personal care assistants of Maine and have a willingness to commit the necessary time to assist the Board.

ARTICLE VIII - COMMITTEES

Section 1: The Board may create committees as needed, such as for fundraising, programs financial matters, or other areas that the Board deems necessary. The Board Chair shall appoint all committee chairs. When possible, the membership of committees shall be an odd number, with the Chair provided the opportunity to cast a tie-breaking vote. Each Committee shall meet at such times and places, and in such manner, as may be convenient for the Committee members.

Section 2 – Executive Committee: The four officers serve as the members of the Executive Committee. Except for the power to amend the Articles of Incorporation and Bylaws, the Executive Committee shall have all of the powers and authority of the Board of Directors in the intervals between meetings of the Board of Directors, subject to the direction and control of the Board of Directors.

Section 3 - Finance Committee: The Treasurer is chair of the Finance Committee, which includes three other Board members. The Finance Committee is responsible for developing and reviewing fiscal procedures, a fundraising plan, and annual budget with staff and other Board members. The Board must approve the budget, containing projected revenues and expenditures, on an annual basis; and all expenditures must be within the budget. The Board or the Executive Committee must approve any major change in the budget. Annual reports are required to be submitted to the Board showing income, expenditures and pending income. The financial records of the organization are public information and shall be made available to the membership, Board members and the public.

Section 4 - Advisory Committees: The Board may establish other committees, including committees consisting in whole or in part of Advisory Directors and non-directors, as it deems desirable, to serve at its pleasure. Each committee shall be advisory to the Board and shall have such powers and perform such functions, not inconsistent with law, as may be prescribed for it by the Board. Appointments to and filling of vacancies on such committees shall be made by the President unless the Board otherwise

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provides. Action by Advisory Committees shall be reported to the Board at its next meeting and shall be subject to control, revision, and alteration by the Board.

ARTICLE IX - STAFF

The Board of Directors shall hire and supervise such staff as it deems necessary to operate the programs of the Association.

1. Executive Director. The Board may hire and supervise an Executive Director, and define his or her duties. The Executive Director shall be present at meetings of the Board of Directors, but shall not vote on any issue. The Board of Directors shall determine the compensation to be paid the Executive Director. The Executive Director may not enter into any contracts binding the Association if the amount of the Contract exceeds \$2,000. The Executive Director may sign checks, except his or her own paycheck, and except for any checks in excess of \$500, which will require the signature of either the Treasurer or the Chair. The Executive Director may be removed with or without cause by a vote of at least 2/3 of the Board of Directors.

2. Other Employees. The Board shall hire such other staff as it deems necessary. The Board may permit the Executive Director to hire and supervise staff.

ARTICLE X – FISCAL YEAR

Section 1: The fiscal year shall be the calendar year (January 1st through December 31st).

ARTICLE XI - AMENDMENTS

Section 1: These Bylaws may be amended when necessary by a two-thirds majority of the Board of Directors, present and voting. Proposed amendments must be submitted to the Secretary, in writing, no later than 14 days prior to voting.

CERTIFICATION

These Bylaws were approved at a meeting of the Maine PASA Board of Directors, August 2004.

Attest: _____.

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Maine Personal Assistance Services Association News

Volume 1, Number 1

November 2002

An Association for Personal Assistance and Direct Care Workers is Launched

Successful gathering provides helpful information

The breakfast for direct care and personal assistance workers held on October 26th in Lewiston was a success. Fifty people came out in the rain on a Saturday to hear about the importance of direct care and personal assistant work and to talk about how an association could support workers and their profession.

Chris Gianopoulos, Director of Maine's Bureau of Elderly and Adult Services, opened the program by recognizing the hard work and dedication of direct care workers. Linda Mills, an independent living specialist who employs her own assistants, gave a personal perspective on personal assistance work and the experience of being the receiver of assistance. Linda captured the audience with her message about respect, dignity and the importance of self-determination. Linda's long-time assistant, Betty Hill, spoke of her own first-hand experience working in the profession of direct care.

Keynote speaker, Di Findley, founder and director of the Iowa CareGivers Association, described her experience as a caregiver and how she started an association that recognizes the professional status and support needs of CNAs, PCAs, Home Health Aides and the many other employees in long term care and home care work. Di's survey work in Iowa and



Workers attending the Association Breakfast Lewiston Auburn College, October 26, 2002

her talk with the audience identified the major challenges to people working in these jobs: Stigma, burnout, low pay and benefits, heavy workloads, isolation, lack of career opportunities and advancement, and difficulties balancing client and employer expectations. Conversations with workers about what they do provided stories of hard work, dedication and a personal message about the importance of this work to the giver and the receiver of care and support.

"My consumer has told me, 'I don't feel like I have a disability when I'm with you.'"

"It's very emotional work that we do. It's so personal, it's almost like part of your family. The hardest part of my job is the emotional part. When I see my [consumer] getting sick or weaker, it hits me right here, and my friends and family don't understand that."

"The work is a constant challenge. Every day is different and you're never bored." (Continue Breakfast side 2)

What could an Association do for workers is Maine?

What the workers said.

- An association will.....
- Empower us to preserve human dignity.
 - Help us address issues like continuity of care and short staffing.
 - Give affirmation.
 - Help us make changes.
 - Provide camaraderie.
 - Other people would view us as professionals.
 - Other people would see us as valuable.
 - Other people would see the people we serve as valuable, including older people, people with disabilities, both children and adults.
 - Our voices could be solidified (and unified) and people would listen.
 - What would we tell people? Pay us what we're worth. Treat us better in other ways also – give us more positive feedback.

(Continued "why" Side 2)

(Breakfast, continued from side 1)

The results from the large group discussion, a questionnaire and the program evaluation support the development of an association for workers in Maine. (see remarks “Why” in the next column)

What’s Next

Elise Scala, Project Coordinator listed the following next steps:

- Workers and members to be recruited. (Funds are available for workers to serve on the committee).
- The toll free number, 800-268-6612 will remain open to take calls from people who want to join.
- Continuing support: Over the next 2 years grant funds will support a part time staff and worker group to form the association and to identify new sources of funds and supports.

Conclusion of the Breakfast

The program ended with an atmosphere of celebration. Names were drawn to award worker recognition prizes and Di Findley organized the attendees for the first Association group picture. Special thanks to Lewiston Auburn College, the Grateful Deli, Mary Eileen Kiniry, Stuart Bratesman, Danny Westcott and Elise Scala (USM Muskie School project staff), Di Findley (Iowa CareGivers Association), and all who participated to make the event a success.

Why an Association (continued from side 1)

Quotes from workers at the first meeting

“An association would help us to preserve human dignity. Our work matters. The people we serve have value and belong in the community. These older people deserve respect from the community.”

“There’s an association for just about every level of health care provider. Family caregivers have their own national association. Consumers, farmers and governors have their own national associations, and yet the largest group of health care providers don’t have one.”

“An association is where you can have your voices heard and where people will listen.”

“I think the association is a great idea. I don’t want it to be just a gripe session. I want the groups to look for answers and the resources to find real solutions.”

“I really think it (an association) is a going to be good thing. We all need that support. The association will make a difference if you, as a caregiver, get involved.” (Susan Tucker, PCA)

News Update: Projects of interest to Workers in Maine

- “Better Jobs, Better Care”, a nationwide funding opportunity to improve the recruitment, retention and quality of direct care workers has been announced by the Robert Wood Johnson Foundation. Groups in Maine are getting organized to prepare proposals.
- Pathways to Retention, a grant funded demonstration project being conducted by Coastal Enterprises, Inc.
- A study of direct care worker wages is being conducted by the Maine Center for Economic Policy. (see enclosed request for participation).
- Direct Health Care Worker Coalition, a group of long term care providers, labor organizations and advocacy groups meeting to address wage, benefit and other issues for direct care workers in Maine’s long term care system.

News for Newcomers:

This project, to develop an association for personal assistance and direct care workers, is funded through a grant from the federal Centers for Medicaid & Medicare Services. The grant partners are the Maine Bureau of Medical Services, Maine’s Plan Development Work Group for Community Based Living and the University of Southern Maine’s Muskie School of Public Service.

For More Information, contact Elise Scala, project coordinator, (207) 228-8423, TTY 228-4880 or call toll free 1-800-268-6612. E-mail: scala@usm.maine.edu

Maine Personal Assistance Services Association News

Volume 2, Number 2

February 2003

WORK GROUP FORMS THE PERSONAL ASSISTANCE SERVICES ASSOCIATION



After a very successful gathering in October 2002, Maine direct care workers decided that they needed an Association to support their profession. The first work meeting was held on Saturday, December 14, 2002 at the University of Southern Maine – Lewiston Auburn College Campus. A heavy rain and busy holiday season did not keep the group from meeting to discuss why the Association is needed in Maine.

The work group, representing over 80 years of combined direct care experience, discussed the goals of the Association. The seven direct care and personal assistance

workers who have taken leadership positions to form the Association discussed its potential, and agreed that improving jobs and working conditions for direct care

workers are top priorities. Other topics on the agenda included discussion of the structure of the association, meeting plans, and the statewide newsletter.

WORK GROUP MEETINGS EVERY MONTH

The Association met for the third time Saturday January 25, 2003. We had a guest speaker, Gail Benvenuta. Gail guided the group through several activities to enhance our communication skills to enable us to build a strong worker association. The group discussed the importance of communicating our needs effectively.

Julie M. reported on the National Alliance of Direct Support Professionals and volunteered to investigate possible membership.

The group discussed this newsletter and suggested including regular features, such as interviews with consumers and a worker advice column. All the members were encouraged to participate in spreading information about the Association through our employers newsletters, where appropriate.

The design of the Association brochure was temporarily tabled until the mission statement is finalized. We have a working draft to be finalized at the next meeting February 22nd.

Stay tuned.
(Trish Richard, reporting)

What is the value of services?

"I love having the company so that I am not alone. And having a PCA in the home meets my individual needs."
(Pam H.)

Interview with Norma Rice-Gould, RN. Page 3

Special Report on the Direct Care Worker Shortage in Maine. Page 4.

You are invited to join us.

Are you a CNA, PCA, HHA, or BS? Do you provide direct care to assist a person with a disability? Call for information about this association, MePASA 1-800-268-6612, TTY 228-8440. Project Coordinator, Elise Scala (scala@usm.maine.edu)



News Update: Projects of Interest to Workers of Maine

- ◆ “Better Jobs, Better Care”, a nationwide funding opportunity to improve the recruitment, retention, and quality of direct care workers has been announced by the Robert Wood Johnson Foundation. Groups in Maine are getting organized to prepare a proposal for workers, consumers and employers in Maine. (see report below)
- ◆ Pathways to Retention, a grant funded demonstration project being conducted by Coastal Enterprises, Inc. is examining workplace culture and how to implement peer-mentoring programs.
- ◆ A study of direct care worker wages is being conducted by the Maine Center for Economic Policy. The report “Without Care: Maine’s Direct Care Worker Shortage” was released February 4th. For a copy, please contact MECEP at info@mecep.org or call 622-7381 (see report highlights on page 4).
- ◆ Direct Care Worker Coalition, a group of long term care providers, labor organizations, and advocacy groups is meeting to address wage, benefit and other issues for direct care workers in Maine. (see report below)

Association Members at the Table:

Patricia (Trish) Richard, Direct Care Worker and Me PASA Member Reporting

“BETTER JOBS, BETTER CARE” Grant Application for Maine

The meetings hosted by Coastal Enterprises, Inc. (CEI) at the Augusta office of the Dept. of Human Services on Jan. 9th and 31st 2003 were well attended by supporters to improve the quality of Maine’s long-term care services. The focus of the sessions was to strengthen the collaboration between the stakeholders to present a strong united front to the Robert Wood Johnson Foundation. RWJ is offering a grant to support the

recruitment and retention of us, the direct care workers.

Many groups agreed to work together on a proposal to present to the Foundation. CEI submitted the pre-proposal application in December, and has been invited to submit the full proposal by February 14th.

This grant is an opportunity for our Association to have a role in planning programs to support direct care workers and to be involved in the implementation of programs like Emergency

Assistance, resource information centers, training and education for workers. Our Association would help keep the project leaders informed of the what services are needed by workers and inform workers of these benefits.

In return we are asking for funds from the grant to hire a coordinator, provide development opportunities for members and pay for materials needed to accomplish our role to support workers in Maine.

Maine Direct Care Worker Coalition: Coordinates State Efforts to Address Worker Shortages

A subcommittee of the Coalition has initiated a bill to increase wages for Direct Healthcare Workers in Maine. While we all know the state budget picture is bleak, we also know that worker shortages and low wage jobs with no benefits will not support the quality of care Mainers deserve. The Maine Center for Economic Policy has compiled research highlighting the care gap and the direct correlation between low

pay/benefits and this increasing worker shortage.

They are saying what we as direct care workers have known for years. Now it’s at a critical level and without drastic changes will only get worse. **This is our chance to be heard.**

Direct care workers and concerned employer and consumer advocacy groups had a chance to speak at the State House on February 4th. to tell Maine legislators about what direct care and personal assistance work is and the

problem of low wages, limited benefits and long hours. A bill will be introduced to ask the legislature to increase wages and benefits. Hopefully the legislators will want to work as hard for us as we do for our communities. This legislation is also to provide funds to promote peer mentoring, training, real career pathways, and workplace culture change. Well, this is my take on what’s going on for our Association at this time, we’re just starting but we have started.

What is the Value of Services?

Dear Readers,

The MePASA members working on this newsletter decided to add a real-life story page to remind all of us how important our work is. On this page we will publish interviews with our clients, letters from consumers and consumer groups. Do you want to tell us about your work? – give us a call or send a letter (for contact information see page 1).

When Work Meets Life...

Diane N., PCA MePASA member, suggested this interview with Norma Rice-Gould, RN

Seven years ago Norma Rice-Gould and her husband made the choice to have her parents reside with them at home. Despite having an already full and hectic professional and private life, the commitment to care for Norma's parents was important to them. So the

– home health workers of all kinds and later last fall, hospice home health care to the end. It has been a very long, but rewarding, seven years; we have learned much concerning the home health process. Nearly every PCA, CNA, RN, social worker, or

“With your help, I was able to continue to have a life...”

process of scheduling health care providers, dealing with insurance companies and various agencies with many regulations, frequent phone calls, and having a parade of health care people come into their home were added to their daily routine. Her father's Alzheimer's Disease continued to progress until he died three years ago and her mother's health continued to decline until this January, when Norma's 94-year-old mother passed away quietly, while sleeping in the comfort of her home and her own surroundings. When asked what kind of a change home health care providers brought in her life, the lives of her family and that of her parents, Norma confided, "We could not have done it without them

week for my mother! It was a slow process - PCA and CNA care made all the difference in the world to me, to my husband, to my parents, and to my family. Without their assistance, I would not have been able to continue to work as I would have had to do all of her care. With your help, I was able to continue to have a life - it has been a lot different - but without home health, it would have been impossible. There are, of course, flaws in the system BUT we will be forever grateful for the system and thankful to all of you."



SPECIAL REPORT

Without Care: Maine's Direct Care Worker Shortage

Maine Center for Economic Policy, Author Lisa Pohlmann

Report Highlights: (full report available at <http://www.mecep.org>)

Who are direct care workers and what do they provide?

- These paraprofessional workers in Maine's long term care system include certified nursing assistants (CNAs), personal care attendant (PCAs), and home health aides who work in nursing facilities, residential and assisted living facilities and home care.
- Together they provide eight out of ten hours of paid care received by elders and people with disabilities needing long term care.
- Their services range from feeding, bathing, dressing, administering medications, and rehabilitation, to helping people with in-home dialing living tasks. They provide emotional support, companionship, and a lifeline to the outside world for some of our most vulnerable citizens.

Workers struggle because of low wages, difficult working conditions, and staff shortages.

- Over one-third of direct care workers are single parents.
- Over half of CNAs and two thirds of PCAs have household incomes less than \$20,000. The average annual income for a PCA is 2001 (\$17,480) was 133% of the federal poverty level for a family of three (\$14,630), and was only 60% of a basic needs budget in Maine for a family of three in 2001 (\$29,018).
- Many are not offered health insurance by their employer or are not able to afford the co-pays of the employer's health insurance plan. Most home care workers do not have guaranteed hours and thus do not receive health insurance or paid time off.
- Many rely on public assistance to get by because of low income. CNAs working in home health agencies and nursing homes are twice as likely to receive public benefits- specifically food stamps and Medicaid – than workers in other job categories.
- With an average hourly wage of \$8.69 for all direct care workers in 2001, many workers are leaving the field, able to find far safer, less physically and emotionally demanding, and potentially more stable work at similar or higher pay in other sectors.
- The 2000 occupational injury rate for these workers in Maine (at 6.9 incidences per 100 workers) is over twice as high as the rate for all occupations (at 3.0 incidences per hundred workers).
- While most direct care workers report liking their work with clients, they do not like the lack of career advancement opportunities, inadequate supervision and support, and the stress of staff shortages that compromise their ability to offer quality care. These important factors are also driving workers away from direct care.

Key recommendations of the report include:

- Coordinate state efforts to address the worker shortage through establishment of a Direct Care Workforce Committee.
- Increase public funding to enable employers to provide livable wages, and ensure benefits for all direct care workers.
- Develop a coordinated training system, career pathways and workplace culture changes.

Special thanks to Lisa Pohlmann for writing this important document and to the funders who supported it: Ford Foundation, Francis Hollis Brain Foundation and the Bingham Program.

The Maine Center for Economic Policy is an independent, nonpartisan research organization with the mission to advance public policy solutions to achieve a prosperous, fair and sustainable economy.

Maine Personal Assistance Services Association News

Volume 2, Number 3

April 2003

MISSION ACCOMPLISHED! STATEMENT – “GOOD, JUST THE WAY IT IS”

The Association met for the fourth time on Saturday, March 22, 2003 in room 106 of hospitable Lewiston-Auburn college of USM. We had a very productive work session. The work group for Maine PASA



On the picture: Elise Scala, Project Coordinator during brainstorming session.

contribute to Maine PASA’s goals. Group members came up with a long list of possible activities to form a coalition, empower workers, respect the dignity of self and others, and to improve the quality of direct care jobs.

Recently the Association represented direct care workers’ interests at legislative sessions in Augusta (see Trish Richards report on page 2). Maine PASA is a working member of the Direct Care Worker Coalition and attends meetings in Augusta. The Association members are scheduling site visits to meet with executives and governing boards of home care agencies and long-term

finalized its mission statement:

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

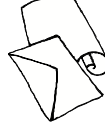
The mission statement guided the discussion of other Association ideas and plans. The work group decided to focus Association objectives on building the capacity of workers and their work and to keep the membership open to anybody who supports the mission statement and is willing to

care institutions.

The work group members are encouraged by these accomplishments and the feedback from others, and are charting an ambitious plan for strengthening and growing Maine PASA. Public relations, recognition and outreach activities are among the top

YOU ARE INVITED TO JOIN US

Are you are a C.N.A., PCA, HHA, or BS? Do you provide direct support or care for a person with a disability? Call for information about Maine PASA 1-800-268-6612, TTY (207) 228-8440. Or e-mail Project Coordinator, Elise Scala: scala@usm.maine.edu



priorities of the group at this time. Plans for May include printing a brochure and arranging newspaper and radio press to help build awareness and community support. Ideas for a Maine PASA logo are being reviewed. The next Association meeting will be held on Saturday, April 19, 9:30 am – 1:00pm at Lewiston Auburn College.

~ QUOTE OF THE MONTH ~

“Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act of caring, all of which have the potential to turn a life around.”

~Leo Buscaglia

Page 2: Improving Quality of Jobs Important long-term care legislature updates

Page 3: Respecting Human Dignity “Next Door” - a real life story that speaks to the value of PCA work and workers

Page 4: Empowering Workers “Dear PASA...” – introducing a new column.

Improving Quality of Jobs

Maine PASA member Trish Richard reports:

Our state legislators have of pay into the direct care field any time soon. Benefits won't be provided to any greater degree than they are now. **LD 1090** gives us the opportunity to change that. A carry over is somewhat better than a dismissal in that we still have a chance to prove to legislators we want this bill implemented. All of us won't directly benefit from this one, however; it's one step to parity in pay and work validation for all of us. If each and every one of us at least picks up the phone, e-mails or snail mails our

legislatures and just tell them "I want your support of LD1090", our voices will be heard as one and that'll be quite loud, don't you think? Pass this on to as many co-workers, friends, and relatives as you know. Remember the legislators are supposed to represent the needs of the people and we are people. Here's to our voices that have been softly persistent for years, being heard as one, a concise and considerably louder voice.

Maine PASA member Julie M. reports from Augusta:

I attended the public Care Assistance Network, a provider group, spoke against passage of this bill. She stated in her testimony that a survey of service consumers showed that 9 out of 10 consumers felt the assistants aiding them had adequate knowledge for the job. She also stated the Maine residents appreciate the services, 'as is,' and recommended the bill ought not to pass. Kathleen Taggart, from "Bridges", representing the Home Care Alliance, also spoke against this bill. In her testimony she stated this bill would hinder the agencies providing the services, that many of the consumers are able to handle their own health care, and that it would create staffing shortages. She also advised that the PCA

training has been increased from 40 to 50 hours (each agency provides their own state certified training), PCAs will be able to use the first 20 hours of this training towards CNA certification.

There was no response when asked if there was any testimony in favor of the bill. It was moved to work session, and unanimously opposed.

Many other bills are being reviewed by the State legislature this year. To learn more about bills, hearing schedules, and to find helpful directions on how to submit legislation check the Maine government website: <http://janus.state.me.us/legis/siteguide/>

Check page 4 to find out how to make your voice heard in Augusta.

What Is the Value of Services?

“Next Door”

Input sought by Diane N., PCA, MainePASA member

Ten years ago I moved next door to my parents, now next-door means in the woods on a quiet dirt road! My sister lived within walking distance and I was in a comfortable relationship thinking life is great when we discovered a big change in my mother. Little did I know that this change would not only affect my parent's life but mine as well.

My mother had Alzheimer's disease and needed constant care. Dad said, "No nursing home, Mom would stay in the home we built together."

My sister had moved out of town and my relationship took a back seat. I started going over to take care of Mom and Dad every night



and during weekends. I could see my Dad was getting very tired and told him we should

Respecting Human Dignity

We have had the opportunity to get to know each other once again which is a blessing for me.

I often wondered if I might be enabling him or treating him like he was a child. I really needed to do some soul searching. I signed up for a PCA class to see if I was doing the right things for my Dad. My PCA class put my mind at rest about my caring for Dad. It really opened my eyes to what I will need to do when

talk to the doctor about getting some help.

My mother was getting worse and was quite a handful to take care of, however he still insisted she stay at home. We finally found a PCA to come in on a regular basis and she took really good care of my Mom. I

“No nursing home. Mom would stay in the home we built together.”

could see my Dad was doing better when I came home to find him working in his shop while our PCA was in the house caring for my Mother!

Dad had become comfortable enough to leave Mom for a while and get some well deserved time for himself. This of course helped ease my mind knowing my Dad and Mom were in good hands. Mom passed away 4 years ago and I still go next door every night to take care of my Dad. Although he still gets around I have noticed some changes.

We play cards every night before dinner, I call it my “check in” time. It gives me a chance to really listen to him and make sure he is doing ok.

the time comes. Becoming a certified PCA was something I needed to do for myself. I want to make sure he gets the same chance my

Mom got, to stay in the home that he and my mother built. I also have a network of Caregivers now that will help me when I need the help.

I know Dad will leave me one day. But till that day happens, I know he is happy and that makes me happy.

As for my personal life, to be honest I really don't think about it, my family knows this is my life and they are “OK” with that! I have the rest of my life to do MY thing, till then I will continue to go next door!!!
~J~



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.

Volume 2, Number 4

June 2003

Maine PASA features New Logo and Mission

Thanks to the input of many, the hard work of the development team, and an artist's touch the logo and statements of purpose for the Maine Personal Assistance Services Association are ready for distribution. The message is that Maine has an organization that recognizes and supports direct care/support and personal assistant workers. Personal Assistance Services Workers', the people employed to provide assistance, personal care, direct support to individuals with disabilities and elders. There are thousands of people in Maine working in the range of jobs that fit within this group. The most frequently used titles, like CNA, PCA, DSP, are listed in the article written by Diane in this edition of the newsletter. While the titles and work settings are varied there are shared

values and responsibilities and common challenges in these jobs. An association offers workers an opportunity to connect with others workers, to be informed and identify issues and needs important to their work and the people they work for, and to participate in building opportunities for personal and professional growth. Maine PASA is learning from other states and organizations, growing from a development team to a statewide membership list and is spreading its wings through the distribution of the newsletter and brochure. Please help us spread the word. Members are available to speak at meetings and brochures can be mailed by request. 1-800-268-6612 or TTY 207-228-8440.

Maine PASA Updates: Regional and National Check-In

Job Fair Preview Session

Members of Maine PASA were well represented at the Health Care Job Fair in South Portland on May 19th. The brochures and sign up sheets, boosted by the enthusiasm of member outreach successfully informed many Fair attendees and recruited over thirty new members!



New England Coalition of Direct Support Worker Associations

Members of Maine PASA have helped to organize meetings with other grant supported association and direct care/support worker advocates in the New England states. Connecticut, Maine, Massachusetts, New Hampshire, and Vermont project staff will meet monthly in telephone conferences to exchange information and experience for recognizing and supporting direct care and personal assistant workers.

Massachusetts Worker Registry Project

A successful website and toll-free call number for recruiting and listing direct support professionals to match them to jobs caring for people with developmental disabilities is being expanded. Maine and other New England states have been invited to assist in the development of the site to expand the geographic area served and to enlarge the listing to be a resource for self-directed consumers to find personal assistants. *(continued on page 2)*

**Check out
this month's
Special Insert:
Direct Care/Support
Job Titles**

Maine PASA Updates: Regional and National Check-In *(continued from page 1)*

National Alliance of Direct Support Professionals

Maine PASA has been invited to join NADSP by adopting the organizations code of ethics. While Maine PASA's mission covers a wider population of direct care workers there is interest in collaborating with the Alliance as its advocacy for quality, dignity and self-determination are shared interests.

Direct Care Alliance

This national coalition of consumers, workers and concerned providers is a leading organization modeling efforts to build a stable, valued and well-trained direct care workforce in long term care. DCA leads the way in supporting the premise that quality of long term care is directly linked to the quality of jobs. Their website, www.directcarealliance.org, and the DCA Clearinghouse is an excellent resource.

Direct Care Worker Coalition Updates: Creating Better Jobs

The Maine Center for Economic Policy (MECEP), an independent nonpartisan research organization based in Augusta and a member of the Direct Care Worker Coalition, has received a Maine Women's Fund (MWF) grant of \$11,500 for a project to improve the compensation and working conditions of direct care workers in Maine's long-term care system. This project has grown from MECEP's focus on the needs of low-wage workers. In the spring of 2002, MECEP, in collaboration with Coastal Enterprises, Inc. (CEI), began building a coalition of key stakeholders - including workers, consumers and providers - to research the direct care worker shortage problem and to advance policy solutions. The MWF grant will support MECEP's work with the Direct Care Workers Coalition and the Bureau of Elder and Adult Services to continue data collection and policy development, and will support MECEP's public education on the issue.

At the May 23rd meeting, Coalition members discussed the direction of their summer study as part of implementation of Maine legislature's recommendations. The Coalition is going to tailor its study to determine the cost of establishing a wage floor (probably \$8.25/hour as was done through BDS for direct care workers) that also includes the cost of the "ripple" effect up the wage scale after a wage floor is set. A research subgroup will meet on June 19th at BEAS, which will be followed by a meeting with the new Labor Commissioner to request the data sources this study needs.

In February we informed you about activities that the Coalition members were involved in the process of applying for the Robert Wood Johnson Foundation's "Better Jobs, Better Care" grant. The Coalition members continue discussing ways of improving PCA jobs, though Maine did not get the grant. The largest PCA agency in the state, Home Resources of Maine, and Sandy River Home Resources recently discussed opportunities for increasing efficiency by sharing training resources and have signed a contract to improve PCA work hours by filling-in on understaffed cases. This initiative will also ensure better coverage for the agencies' customers.

Do You Need Health Insurance Benefits? Watch for Dirigo Health Insurance!

Direct care workers and personal assistants working part-time hours, earning wages that make insurance premiums unaffordable, and/or who work for small employers may get some relief from the state's new plan to expand access to affordable health care coverage for Maine residents. Governor Baldacci is acting on his plan to reform health insurance in Maine and is leading the effort to enact a comprehensive, affordable, subsidized package of insurance benefits for Maine's small business community and individuals who do not have access to job-based coverage. The plan covers all state mandated benefits including mental health services and includes expansion of MaineCare (Medicaid) eligibility. For up-to-date information on the plan, check www.fchn.org, ask your employer for information on their participation, and check the next edition of this newsletter.

Energize for Healthy Living

by Roberta R., Maine PAsA member

Energy is strength, force, and the vitality of expression in our lives. Here are some suggestions for recharging energy for your body, mental capacities, and soul.

Tips for Feeding the Body

Start the day off with a good breakfast to recharge the blood sugar levels and provide the energy to start the day. Pack a picnic for work with fruits and vegetables. They are low in calories and high in energy. If you travel, find a beautiful place to have a quiet picnic to revitalize the soul. Nature can be quite entertaining. Empty, chemical-laden junk foods do nothing but satisfy a temporary craving, real food satisfies your soul and feeds the body. Plan peanut butter in your meal routine as it is a high-energy food and makes a nice snack. Showering in body temperature water for 2 or 3 minutes and then lowering the temperature for 15 to 30 seconds (repeat twice) will boost your energy.

Tips for Feeding the Mind and Spirit

- ✔ Lend a helping hand.
- ✔ Wear red, orange, or yellow to bring happiness in your day. Plan a change of scenery, spending time doing what you want to do, like visiting a museum, looking for antiques, enjoying yard sales, picnicking in nature, reading.
- ✔ “Never esteem anything of advantage to you that will make you break your word or lose your self-respect.” - *Marcus Aurelius Antoninus*
- ✔ Practice self-affirmations every day to keep yourself in good spirits (like “I am a smart and talented go-getter”, “I am calm and relaxed no matter what the circumstances are”).
- ✔ Letting go is an important skill to start the healing process and lighten the heart. It takes a lot of strength and courage but it opens our hearts to new opportunities. Listen to your heart, it knows what you need.

- ✔ Get in touch with nature. For example, ride a bike, shovel snow, mow the lawn, rake the leaves.
- ✔ Boredom can bring on chronic fatigue. Stimulate your brain, nourish your creative spirit.
- ✔ A good heart-to heart talk will bring back good energy and restore your connection with other people. Write a letter to a long-lost friend or relative.
- ✔ Plan a special event, so when stress strikes, you will recall the planned event for the future.
- ✔ Work on being a life long learner. Knowledge is power. Empower yourself with reading, going to the movies, and plays. Visit your hometown amenities, they have a lot of information to enrich your life, it’s there for the taking.
- ✔ Finally, we must remember everyday we are noble people doing noble work to make changes, one person at a time.

Life Story

input sought by Diane N., Maine PAsA member

I decided I needed a new career in August of 2002. I wanted to work with and take care of people, whether they were young or old. So I quit my job of being a receptionist and looked into working in the health care field. I was considering training to become a CNA, but was not sure whether it was a career I wanted and would enjoy. I applied at different hospitals and nursing homes as a PCA and I got hired at The Lamp Alzheimer’s Residential Home as a PCA. They hired me knowing that I had no experience, they just saw that I was a caring and loving person. So, The Lamp gave me a chance. While employed at The Lamp, I took an RCS1 course and found that I really enjoyed and loved what I’m doing. I took a CNA course to further my education. While taking my CNA course, I worked part-time and took care of my family at the same time. Though at times everything was very frustrating, my family kept encouraging me to keep going and telling me that everything will be fine. Here it is May, 2003, and I’ve accomplished what I’ve wanted to do. I work as a CNA at an elderly retirement home and I love everything I do. So it doesn’t matter who you are or where you are in life. If you put your mind to it, you can accomplish anything you want.

Sincerely, SC

Special Insert

Maine PASA Newsletter

June 2003

Direct Care/Support Job Titles

by Diane N., Olga G., and Elise S.

One of the challenges of organizing Maine PASA and raising people's awareness about direct care and personal support work and workers has been to explain who direct care /support and personal assistants are. Diane took on the challenge of finding and defining the many job titles used in the health care, home care, residential and assisted living facilities, and the range of support services available to people with disabilities and elders in Maine. This was an interesting task and she found that changes are being made in job titles and educational requirements, and that skills and experience may cross job settings and titles. We recommend that if you're looking for a job or entering the field of direct care and personal assistance that you don't limit yourself to specific titles. Your skills may apply to multiple titles and in more than one work setting. Be sure to call the human resources manager to see if you qualify. And don't feel badly about being a little confused about the titles and educational requirements; you're not alone. Many people were contacted to prepare this listing and to provide general reference information. The information is subject to change. One general source is the National Occupational Employment and Wage Estimates prepared by the U.S. Department of Labor Bureau of Labor Statistics (www.bls.gov/home.htm) and the Maine Department of Labor's Job Bank (www.wajb.org/me).

BS I (Behavioral Specialist I)

Education: High school diploma or equivalent plus completion of a 50-hour approved training program (employers may help you get the training while employed).

General Description: Often part-time. Provides in-home and community-based support for children with emotional and/or behavioral disabilities.

Wage: \$9.50–\$12.00

DSP (Direct Support/Service Professional)

Education: High school diploma or equivalent plus a valid driver's license and good driving record. Some employers prefer First Aid and CPR training and previous experience. Employers are willing to train.

General Description: Provides support to adults with mental retardation.

Wage: \$8.15 (rates vary with title, experience, setting and region)

DSS (Direct Support Staff)

This is a general title used for job posting with Maine's Job Bank.

Education: High school diploma or equivalent, valid driver's license.

General Description: Provides support to people with disabilities and elders with personal care, activities of daily living and socialization, and provides transportation.

Wage: \$8.15

HS (Habilitation Specialist) >NEW TITLE<

Education: High school diploma or equivalent plus relevant experience. (A requirement for the 50-hour training, described above for the BSI, is being considered by MaineCare.)

General Description: In-home and community-based support services for children with mental retardation and autism.

Wage: Not available at this time.

In-home Support Specialist

Education: High school diploma or equivalent and experience (Bachelor's degree preferred).

General description: Provides assistance to children with mental retardation in the home/family setting, in coordination for family/parent caregivers.

Wage: \$10.00 – 13.00

MHRT and MHRT/Community Certificates (Mental Health Rehabilitation Technician)

Refers to the certificate courses, procedures and approved programs established in Maine for mental health practitioners.

Please see <http://muskie.usm.maine.edu/CH/MHRT/communityguidelines.htm> for complete information.

PSS (Personal Support Specialist)

Refers to a training course and not commonly used as a job title at this time.

Education: The curriculum is a recently developed program that combines PCA and RCS courses in a standardized curriculum for people working in either home health, assisted living or residential care settings. The use of the title becomes effective September 2003 and allows the first 20 hours of the PSS course to satisfy the first 20 hours of training in a CNA course taken within 2 years.

PCAs and RCSIs should check on retraining needs if they have not worked in an assisted living facility or home health.

General Description: The curriculum is for people who provide personal care assistance to people with disabilities and elders.

Wage: Requirements expected in September 2003, wage ranges are not available at this time.

RA (Residential Advisor)

Education: High school diploma or equivalent and experience.

General description: One of many titles used by agencies for their staff who provide assistance to children or adults with mental retardation living in residential/group homes.

Wage: \$8.50–\$11.00 (Senior RA level)

RCS (Residential Care Specialist)

Refers to a training course that has been replaced; see PSS for updated information.

Vocational Resource Specialist (Business Development Specialist and Employment Specialist)

Education: High school diploma or equivalent and experience, with varied requirements for driver's license and post-secondary education and preference for Bachelor's degree.

General description: Provide assistance to adults with disabilities to find and keep employment.

Wage: \$9.00–\$11.00 (varies with position, qualifications, agency, and region)

CNA (Certified Nursing Assistant)

Education: High school diploma or equivalent plus the Board of Nursing approved program that involves 150 hours of classroom plus clinical time. Successful completion of the training results in certification and listing on the Maine CNA Registry. Continuing education requirements are 12 hours of training and 8 hours of work every year to stay certified.

General Description: Provides care under the supervision of an RN, in a hospital, nursing home, home care and in assisted living facilities.

Wage: \$9.12–\$10.35

CNA-M (Certified Nursing Assistant trained to pass medications)

Education: CNA training requirements plus an additional 120 hours in a Board of Nursing approved program, plus work experience (1 year full-time or 2 years part-time). Continuing education requirements: CNA plus an 8-hour class every two years for recertification.

General Description: Under the supervision of an RN provides the services of a CNA plus can distributed certain medications in a long-term care setting only.

Wage: \$9.12–\$10.35

CRMA (Certified Residential Care Medication Aide)

Education: High school diploma or equivalent plus an approved 24-hour program.

General Description: Under direct supervision of an RN; passes medications and performs other duties as trained and directed by the supervisor in residential care or assisted living facility only.

Wage: \$8.11–\$10.18

MT (Medication Technician)

See CNA-M.

HHA (Home Health Aide)

Education: High school diploma or equivalent, plus Board of Nursing approved; CNA training (150 hours plus clinical experience).

General Description: Provides services ordered by a physician and under the supervision on an RN in the home setting. Duties include personal care assistance, assistance with therapy, prosthetic care and dressing changes.

Wage: \$8.43–\$9.31

Homemaker

Education: No requirements.

General description: Provides assistance for housekeeping to people receiving services in their homes.

Wage: \$7.00–\$7.50

PCA (Personal Care Assistant)

Education: Health care agencies/facilities require PCAs to have a High school diploma or equivalent plus a 40-hour approved training course taught by an RN. Others will hire PCAs without educational requirements.

General description: PCAs employed in-home care and assisted living or residential care facilities are supervised by RNs to provide assistance with personal care, activities of daily living, provide transportation and may perform light housekeeping work.

Wage: \$7.50–\$8.75

RES 1 (Residential Care Specialist I)

Education: High school diploma or equivalent plus 36 hours of approved training.

General description: Provides personal care assistance to assisted living residents.

Wage: \$7.72–\$9.81

Psychiatric Aide (Mental Health Assistant CNA)

Education: CNA requirements, basic life support certification, MH experience recommended.

General description: Assists people who are mentally impaired or emotionally disturbed in a facility setting under the supervision of an RN or medical staff.

Wage: \$11.04

CHW (Community Health Workers)

Other titles for frontline paraprofessional work in community/public health and health promotion include Lay/Peer/Community Health Advisor or Aide, Home Visitor, Health Advocate, Community Health Representative (CHR) and Public Health Aide (PHLA).

Education: Positions vary and may be volunteer or paid depending on program/service

General description: Employees in the health care system who serve as community members and work in the community setting to serve as connector between health care consumers and providers to promote health among groups that have traditionally lacked access to adequate care.

Wage: Positions vary and may be volunteer or paid depending on program/service.

Consumer Directed Attendant

Education: Varies based on consumer preference and need.

Training is provided by the consumer.

General description: Attendant is hired on an individual basis (not through an agency) by a consumer to provide services to assist a person with disabilities to live in their home and to support independent living options.

Wage: The average CD-PAS wage for Personal Care Attendant is \$7.70/hr.

Informal and/or Paid Caregivers

Many people provide services to individuals with disabilities and elders who need assistance in their homes and with activities of daily living. Most workers are family members and friends and the arrangements do not include (formal) employment. Some people do receive payments through private arrangements. The qualifications and payments vary widely and most individuals and families are extremely thankful for the help.

Books Recommended by Maine PASA Members

Searching for something special to enrich my life and those around me, I found the book, *Midwife's Tale: the Life of Martha Ballard, Based on Her Diary, 1785-1812*, written by Laurel Thatcher Ulrich. Reading Martha's diary entries, I spiritually walked with her to the local families while she delivered babies. Martha went out in all types of weather. She was committed to birthing babies. As I followed her from home to home I learned she had patience with different values and beliefs. As I read about Martha's life, I too, realized over the twenty years of working in elder's homes I was making a difference on a lot of people just like Martha. (Robertia R.)

The Fall of Freddie the Leaf by Leo Buscaglia, Ph.D., chronicles the change of life and seasons for a leaf named Freddie illustrating the delicate balance between life and death. Excellent for children and adults dealing with end of life situations. I bought it for my Nana as she was dying with terminal cancer and she requested that it be read to her over and over. Very special reading. (Diane N.)



You're Invited to Join Us!

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

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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.

Volume 2, Number 5

August/September 2003

Maine PASA puts its Mission and Purpose to Work

The last newsletter featured the new Maine PASA brochure. We are pleased that so many people responded to the mailing by sending us membership information. The purpose statements printed in the brochure are now guiding the development workgroup to plan activities to fulfill our mission; to form a coalition, empower workers, build opportunities, respect human dignity and improve the quality of our jobs. The goals will now serve as subject areas for the Maine PASA 2nd annual conference day; *People in Direct Care, Support Work and Personal Assistance: Building Our Capacity, Valuing Our Work*. Mark your calendars: November 14th 8AM – 4PM, with half day sessions an option. The event will be held at Southern Maine Community College in South Portland, and scholarships for long distance travel and lodging are being arranged.

SAVE THE DATE! November 14th

PCAs, CNAs, Personal Attendants,
PSS, DSPs, HHAs, CRMAs,
Homemakers and other direct care
and direct services personnel...

Maine PASA is planning an event for you!
Watch for news and call us for brochures
at (800) 268-6612.

Spotlight on Direct Care and Support Workers

Events in Maine and across the country are focusing on the value of direct support workers in long term care and community services for people with disabilities and elders.

- Better Jobs Better Care Grants: Five states have been awarded a total of \$7 million to demonstrate methods to improve the recruitment and retention of direct care workers. The program, supported by the Robert Wood Johnson Foundation and Atlantic Philanthropies, granted the awards in July to Iowa, North Carolina, Oregon, Pennsylvania and Vermont
- The federal Centers for Medicare & Medicaid Services is responding to concerns for workforce shortages and seeks proposals for the Demonstration to Improve Direct Service Community Workforce. Maine has responded to the solicitation and the Governor's Office of Health Care Policy & Finance submitted a proposal in August to address health insurance coverage and retention programs in home health agencies in Maine. This is a national competition and award notices are expected in early October.

**For the latest news on direct care worker topics
and Voices from the Frontline:
See www.directcareclearinghouse.org**

Upcoming Events in Maine

- **September 23rd: Excellence in Resident Care Conference, Augusta Civic Center**
Educational topic and recognition awards; Understanding & Managing Challenging Behaviors in the Long Term; Care Setting. Sponsored by the Maine Long Term Care Ombudsman Program and the Maine Health Care Association. For information call 623-1146.
- **September 24th: Building Alliances for Healthy Aging, Augusta Civic Center**
A conference on healthy aging and alliances to support programs. Sponsored by Maine Department of Human Services, Bureau of Elderly and Adult Services, USM Muskie School's Maine Nutrition Network, and Partnership for Healthy Aging. For information contact Claudia at 626-5036.
- **October 7th, 7:00a-5:30p: Healthcare Jobs and Education Fair, Holiday Inn By The Bay, Portland**
Sponsored by the Healthcare Review.
- **October 15-16th: Direct Support Professional Conference, 16th annual event, Bangor Civic Center**
Topics and presentations for Direct Support Professionals in MR. Sponsored by the Maine Department of Behavioral and Developmental Services and the USM Muskie School's Center for Learning. For information contact Melanie at 626-5244.
- **November 14th: People in Direct Care, Support Work and Personal Assistance: Building Our Capacity, Valuing Our Work, Southern Maine Community College**
Sponsored by Maine PASA (the association that brings you this newsletter). For information call Maine PASA at (800) 268-6612.

From Muskie School of Public Service to Maine PASA

Many of you know that the Maine PASA project is funded through a grant from the U.S Health and Human Services, Centers for Medicare and Medicaid Services as a part of the Real Choices System Change Grant in partnership with the Muskie School of Public Service, USM.

The Muskie School is a well-known research center, and it trains health care policy analysts and managers. It is not surprising that the School has a great interest in the development of the Maine PASA project, as both focus on improvement of quality of health care and health care jobs. The School supports the Maine PASA in many ways – from providing facilities for business meetings to technical support and expertise. The Association owes a great part of its success to a project coordinator from heaven – Elise Scala. Thanks to her

commitment, resourcefulness and energy, the Association moved from a wonderful idea on paper to a real-life, powerful tool for bringing personal assistants together to reach their goals. One of the Muskie School's graduate students, Olga Gross, has been working with the Association since November of 2002. Currently Olga's assignment is to present the Maine PASA with a strategic business plan by December of this year. The key steps of the process are to analyze implications of non-profit status for Maine PASA, explore networking opportunities and establish relationship with organizations providing advice and technical support in non-profit development; interview other worker associations (Iowa, North Carolina, Vermont, New Hampshire, Connecticut) and define how their experiences could be applied to the development of Maine PASA.

Books Recommended by Maine PASA Members

She Took To The Woods by Alice Arlen is a biography and selected writings of Louise Dickinson Rich. Arlen writes with a wonderful flow about Louise's life, pointing out her passion and flair for writing stories. Louise, born in 1903, lived in the era of our elder population here in Maine, so many of our elders can relate to her short stories of hardships during the depression, fierce winters, relationships, and wartime rationing. This book will give an understanding of Women's history with the use of the early technology, community life, and caring for one another. The short stories are only two or three pages long and are easy to read to elders to use as a medium for connecting with your elder. The stories may bring back long forgotten memories that elders enjoy sharing. For a little while there is no loneliness, and boredom of the mundane. (Roberta R., PCA)

Maine PASA Updates

The development workgroup is meeting and planning opportunities for direct care and support workers in Maine. Since our last newsletter:

1. Maine PASA is now listed as one of the worker associations in the country. (See www.directcareclearinghouse.org/worker_assoc.jsp)
2. Maine PASA's development workgroup meets monthly to discuss the future of the association as a non-profit organization and the November conference.
3. Maine PASA participated in the State's development of a grant proposal, Providing Health Coverage and Other Services to Recruit and Retain Direct Service Community Workers in Maine: The Dirigo Difference.
4. Maine PASA has arranged for scholarship awards to support workers to attend conferences in the State.
5. Maine PASA participated in the New England Coalition of Direct Care & Personal Assistants Worker Associations.
6. Maine PASA was interviewed by the Paraprofessional Healthcare Institute for an upcoming national report on worker associations.
7. Maine PASA representation was requested at the meeting of Maine Joint Advisory Committee on Select Services for Older Adults (MEJAC) Initiative. (See full article on this page.)
8. The membership keeps growing. If you have not completed a membership entry form, please call Maine PASA at (800) 268-6612.
9. Maine PASA members have presented to staff groups and are available to meet with your organization. Call us to learn more at (800) 268-6612 or in Portland at 228-8423.



The Maine Joint Advisory Committee on Select Services for Older Adults (MEJAC) Initiative

by Robert R., Maine PASA member

The 119th Maine Legislature authorized the Maine Joint Advisory Committee on Select Services for Older Adults to conduct a study of the care options for persons with dementia and the challenging behavioral issues that can be associated with their cognitive impairment.

Difficult behaviors that can arise in the person with dementia are potentially harmful to staff and family members and can subject administrators to liability and occupational health and safety (OSHA) issues. Demographic trends imply that these problems will grow over time as Maine's population ages, because dementia is more prevalent with age. The MEJAC's subcommittee will focus on the care needs and options for developing and improving programs and services for older persons with cognitive impairments and the behavioral issues associated with those impairments.

The Maine Alzheimer's Association initiated the legislative document (L.D.) 1075, *An Act to Ensure Appropriate Care for Older Persons with Dementia* in response to growing reports of persons with dementia who develop challenging behaviors. Frequently, these people wind up in hospital emergency rooms in crisis, are admitted to the hospital, and remain there for weeks on end because an appropriate and safe placement is not available. The MEJAC will report back to the legislature in December 2003 and 2004 with recommendations and options for developing and improving programs and services for these people.

At the August meeting, the Committee addressed issues of worker and client safety in various community settings, consistency of care, implications of gaps in care for the clients' families. Discussions were focused on the proactive approach to support and training needs. Applying the guiding principles of the MEJAC, the Committee members brainstormed the opportunities for improvement of care options for people with dementia and behavioral issues.

Maine PASA Development Workgroup (from left to right): LuAnn, Trish, Olga, Gail, Susan, Roberta, Kim, Julie; missing: Elise, Jon

For Goodness Sake: A Daily Book of Cheer for Nurses' Aides and Other Who Care

by *Bethany Knight, CNA*

Entry for September 7

The great truths are always very basic. Know thyself. Do unto others as you would have others do unto you. Look both ways.

Being in a good mood makes life easier. That's a great, basic truth. No matter how good your reasons are for being mad, grouchy, sad, or numb, they can't compete with the superiority of being in a good mood.

Of course, experiencing a tragedy is not something we can pop out of in an hour or a day or even a week. We all need time to heal and accept our terrible loss.

Bad moods brought on by stupid things are so unnecessary, and yet they are a common cause of suffering.

Saskia Davis recommends we choose a different kind of suffering—suffering from inner peace. What are the symptoms of this malady?

A tendency to think and act spontaneously rather than on fears based on past experiences.

An unmistakable ability to enjoy each moment.

A loss of interest in judging other people.

A loss of interest in judging self.

A loss of interest interpreting the actions of others.

A loss of interest in conflict.

A loss of ability to worry (this is a serious symptom)

Frequent, overwhelming episodes of appreciation.

Contented feelings of connectedness with others and nature.

Frequent attacks of smiling through the eyes from the heart.

An increasing tendency to let things happen rather than make them happen.

An increased susceptibility to the love extended by others as well as the uncontrollable urge to extend it.

TODAY: Suffer inner peace.



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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Volume 2, Number 6

November/December 2003

Annual Event Gets High Marks and Attendees Get Recognition and CEUs

Maine PASA hosted its 2nd conference in Lewiston on November 14th. There was side-splitting laughter, applause, involved discussions, words of thanks and conversations, good food, door prizes, a relaxing massage, and a clear message: Direct care, direct support and personal assistant work requires skill and personal commitment and the people who do this work deserve respect, recognition, support, and need to take care of themselves.

Presenter Ed Latham, former CNA, RN, educator and humorist, demonstrated the stance needed to show yourself and others what direct care and support work is all about. When you tell them you're a CNA and they reply "Oh, I couldn't do that," you confidently say, "You're right. You couldn't." (Remember that expression and head nod Ed demonstrated? Go ahead, give it a try.)

The day-long program, Building Our Capacity and Valuing Our Work, was organized by the Maine PASA development team, a group of direct caregivers and direct support professionals working with the support of a federal grant. The members of this group were recognized at the opening of the day. The program was a successful demonstration of Maine PASA's purpose and vision. Here is what some participants told us: *"Thank you. I needed that. (I'll give it back.)", "Very enjoyable. Great learning experience.", "Great workshops.", "I loved this seminar.", "This was awesome. Wonderful presenters, wonderful, wonderful workshops."*

Spotlight on Direct Care and Support Workers

by Linda Davis, PCA and Conference Attendee

When I filled out the form to attend the Maine PASA conference in Lewiston last month, I wondered if it would be worth losing a day's pay. I vaguely remembered registering to be a member of the Maine PASA, mostly because it was free. Anytime a group of people join forces to benefit me, I have always felt the cause was worthwhile. So, on November 14, I found myself one of four other HRM employees sitting around a table at the University of ME, Lewiston.

I did not have to wonder long. As speaker after speaker told us, this organization was founded to help anyone who works in the direct care, support, and personal assistant field. That's us. One thing was stressed all day: whether you clean houses, empty commodes, bathe, dress, get meals or do shopping for consumers, you need to start referring to yourself as a professional. If we don't value ourselves, how can we expect those in power positions to support us with better benefits and wages?

At the last session, "The Value of an Association," the group decided there were many reasons Maine PASA is needed. Some are that it gives us opportunities to learn what is happening in our field, how we can impact the changes, and what effect policy changes have on us. While one person may not make a difference, many with the same concerns do. The association can bargain for better salaries and benefits. Associations provide a forum for workers to exchange information and stories, to understand teamwork, to reduce the isolation the job so often entails, and to make workers aware of what is happening in the field.

What did I learn? For one, that in our jobs as PCA's we hold the dignity of a human life in our hands. We were encouraged all day to value the gift we have to give, and to name ourselves Professional caregivers. One PCA from Iowa said "My Ph.D.? I preserve human dignity." And probably the most important lesson was to keep your sense of humor. Norman Cousins said it best: "An adequate share of humor and laughter represents an essential part of the diet for a healthy person." This day made me proud to be a PCA/homemaker for Home Resources of Maine. When the opportunity comes again, I won't have to wonder if the day will be worthwhile.



Ed Latham presents at the 2nd Annual Maine PASA Event



Rod McInnes receives a massage from John Moulton at the Maine PASA Event

Fall Events in Maine Highlight Direct Caregivers, Direct Support Professionals and Personal Assistants

- The Maine Long-term Care Ombudsmen and Maine Health Care Association co-sponsored a very well attended program in Augusta on September 23rd. A nomination and award program was recognize five direct care workers: Barbara Colby, CNA, Alzheimers Care Center; Gardiner; Tamara Ehler, RN, Oceanview Nursing & Residential Care, Lubec; Trent Gay, CRMA Woodford Street, Portland; Lorraine Langlois, LPN, St. Marguerite D'Youville Pavillion, Lewiston; Tina Linscott, CNA-M, Falmouth by the Sea, Falmouth.
- The Maine Department of Behavioral and Developmental Services sponsored the 16th annual event for direct support professionals in Bangor October 15-16. Maine PASA presented a workshop at the event, sponsored a display table and recruited new members.
- LD #1090 work is carried over: Resolve, To Promote Recruitment and Retention of Direct Care Workers in Long-term Care in Maine. Sponsor: Senator Beth Edmunds. A survey to assess the need to set a wage floor (\$8.25) for direct healthcare, workers and the potential cost to the State.
- Legislative Request: "An Act to Enhance Home-based Supportive Services to Promote Independence for Maine Citizens." Sponsored by Beverly Daggett. This bill proposes to improve the quality and availability of home-based supportive services for Maine seniors and citizens with disabilities in order to promote greater independence. The bill proposes increases in the availability of consumer-directed home-based supportive services when this service option is appropriate.
- Maine State Employees Association (MSEA) co-presented with Alpha One on the topic of consumer directed options for personal assistance services and the potential for organizing workers under MSEA and SEIU (Service Employees International Union) to ensure State sponsored benefits for personal assistants and solidarity with consumer-employees.
- Maine PASA recognized: The Eastern Maine Chapter of the National Gerontological Nursing Association (NGNA) extended a proclamation of welcome to Maine PASA for the November program and collaboration on projects of mutual interest.
- NEW GRANT! Maine was one of only 5 states awarded a grant to study the impact of health insurance and other human resource services on the recruitment and retention of direct services workers. The 3 year grant will provide incentives and support for a targeted group of employers in home and community based services to enroll in the newly created Dirigo Health Program and the Employer of Choice program. This grant will also support the development of the Maine PASA website and member participation in grant activities. For more information contact Maine PASA.

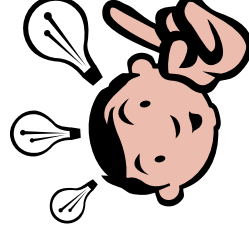
A Call For Stories

Maine PASA would like to feature stories about people who are direct caregivers, direct support professionals and personal assistants on our website. We want to recognize the people who do the work, be able to tell others about the work, the dedication and the true value of these jobs, and the people who do them. If you know a co-worker or friend who is employed to provide assistance or direct care to an elder or person with a disability who you think does a great job please write and tell us about what they do. Why would you want this person helping you or caring for your family member? We would like to hear about your work too. What can you say that would help to recruit someone to be a direct care, direct support or personal assistant? Please send your stories to [Elise Scala \(scala@usm.maine.edu\)](mailto:Elise_Scala@usm.maine.edu) or Maine PASA, P.O. Box 1881, Portland, ME 04104). Please include your phone number so that we can notify you if your story has been selected for inclusion.

Think About It

Maine PASA's mission and purposes are to...

1. Form a coalition by bringing diverse members of the workforce together around a mission of opportunity, respect, empowerment, human dignity and quality.
2. Empower workers by providing a place to share common goals.
3. Build opportunities for members to gain knowledge and skills to attain personal and professional goals.
4. Improve the quality of our jobs by promoting recognition of workers and the value of their work as a professional based on caring and quality.



Tell us how Maine PASA can recognize direct care support and personal assistants!

What Would You Like an Association to Do for You?

“Maine PASA should.....”

(top 5 responses from Annual Event survey)

1. Provide a job seeking service.
2. Provide a place to meet and talk to other people who do similar work.
3. Build support for improved wages and benefits.
4. Offer programs for work related training.
5. Build public awareness of the value of assistant/ support and direct care work.

And what is Maine PASA planning to do?

(top 5 responses from Annual Event survey)

1. Our new website, www.maine-pasa.org, is being developed to provide a place for people to learn about direct care, support and personal assistance work, the people who perform the work, opportunities for employment, education and training, policies that affect jobs and services and links to the state and national experts.
2. Maine PASA is making the transition from a grant funded project to a non-profit organization. The structure and functions of this organization will support worker involvement and will build public support for the mission and purpose of the association and for its members.
3. Maine PASA will support members to attend meetings and to participate in the Direct Care Worker Coalition, the Workforce/Dirigo Demonstration Grant, the Maine Joint Advisory Council, and other policy and practice initiatives in the Maine that need input from direct care and support workers.
4. Maine PASA will continue to produce the newsletter, speak to groups, recruit members and plan events of interest to members and workers statewide.
5. Maine PASA will communicate with state and national leaders on issues and initiatives that can contribute to the recruitment and retention of direct caregivers, direct support professionals and personal assistants and efforts to improve the quality of jobs and quality of care, and recognize the people who work in this jobs.

How to Become a CNA

by Susan Tucker, PCA
Sandy River Home Resources

I became a PCA two years ago for Sandy River Home Resources. I never thought I had the confidence in myself to do this kind of work. But I gave it a shot because I had been out of work for seven years. I was a stay-at-home mom with a special needs child, who receives home based services himself. I was going through a rough time in my life along with my son. I had been looking at applying for other positions. This work happened to fall in my lap. I went through the training and took the exams required by the State.

My friends and some of my family said “Oh it’s a lot of hard work” and “Oh by the way you’ll never make it.” Well, I can say it now. They are opening wide and inserting a foot in their mouths. I’ve met many people in my journey as a PCA. Sometimes you go into someone’s home just for a one-time deal and feel like you’ve known your client your whole life.

Having the experience of being a PCA for more than 2 years and now studying to become a CNA, I can say that this type of work is not for everyone. It takes someone special. If you work for an agency, ask your administrative support staff when and where CNA classes are being offered.

I was lucky to have asked and gotten a good answer, and my classes are held at Pine Point Nursing. There was one other place they were offering CNA classes - Sedgewood in Falmouth. Some agencies might help you with reimbursement for the course. If Adult Ed is involved, the course is free. You only pay for your books. The facility puts on an open house and you get to ask questions and get a tour of the facility. You pick up an application to become a CNA student candidate. You may need to have an interview and take a competency test to get into the program. If you pass the test, they will call you. If you do not work for an agency and are considering becoming a CNA, check for courses at your local adult education program or community college.

This is a 150-hour course. You need to pay attention in class and read the chapters that are assigned. Do the review questions in the back of each chapter. Participate in labs and clinicals is a must in order to succeed. You must pass all quizzes and take a final exam for the State. You must also register with the State. But if for some reason you decide you do not want to become a CNA and have been in the course, you can get 20 hours of credit towards becoming a PSS (Personal Support Specialist). Then all you would need is another 30 hours of course study to qualify for your PSS.

I will graduate in December 2003 with a CNA certificate. They will be starting another CNA class in January 2004 at Pine Point Nursing in Scarborough. The person to contact is Anne Arrenstein, RN. She is the CNA instructor.

**Announcing the
Maine PASA website!!**

*Currently under construction!
Coming to a computer near you!*

www.MainePASA.org

National News

- **Direct Care Clearinghouse**
This national newsletter and website provides reliable, current information related to direct care. Tune in and be informed:
<http://www.directcareclearinghouse.org>.
- **Boosting Care Quality Through Workforce Development**
Nov. 7, 2003 - A recent paper, "Why Workforce Development Should be Part of the Long-Term Care Quality Debate" (Robyn I. Stone, Steven L. Dawson, and Mary Harahan), argues that workforce development activities to help direct-care workers participate effectively in long-term care settings should be integrated into all quality improvement efforts. To read a copy of the paper, go to:
http://www.directcareclearinghouse.org/r_art_dct.jsp?res_id=62910
- **House and Senate Pass DSP Recognition Resolution**
The Direct Support Professional Recognition Resolution, a concurrent resolution, was passed this fall by both houses of Congress. To read the resolution, go to <http://directcare.c.tep1.com/maabHmfaa2plea97MUe/>. For details on the resolutions or other aspects of ANCOR's national advocacy campaign, go to <http://directcare.c.tep1.com/maabHmfaa2plfa97MUe/>



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!
Maine PASA, P.O. Box 1881, Portland, ME 04104
Voice: (800) 268-6612, TTY: (207) 228-8440, Email: scalaf@usm.maine.edu



Maine PASA
P. O. Box 1881
Portland, ME 04104

Editorial: Am I A Professional?

by *Roberta Record, PCA and Maine P-ASA member*

Dear Readers,

I have been pondering and talking with people about the word *professional*. I asked the question, is a person doing direct care and personal assistant work, making between \$7.50 and \$9.00 per hour considered a professional? I went to the dictionary and found these definitions:

Profession:

1. A calling or occupation requiring specialized knowledge and advanced education.
2. The body of persons engaged in such an occupation.
3. A principal calling, vocation, or employment.

Professional:

1. Characterized by or conforming to the technical or ethical standards of a profession.
2. Participating for gain or livelihood in a sport or activity often engaged in by amateurs.
3. A person who is expert at his or her work.
4. Having a particular profession as a permanent career.
5. Engaged in by persons receiving financial return.
6. Following a line of conduct as though it were a profession.

Professionalism:

1. Professional character, spirit or methods.
2. The conduct, aims or qualities that characterize or mark a profession or a professional person.
3. The following of a profession for gain or livelihood.

While participating as a Maine P-ASA representative in a meeting of professionals discussing the problems of challenging behavior of people with dementia I ponder this question of professionalism. It is very important to be a professional.

Direct care, support and personal assistant workers have a lot at stake in taking care of vulnerable people and assisting people with disabilities to live independently. I acquired specialized training to do this work. I am required to follow technical and ethical standards. I go into peoples' homes/lives who need my help and they expect me to be an expert. I do this almost everyday and have been for years. There are thousands of people who do this work. I get paid for the work I do, by my employer who expects me to uphold standards of conduct. For the rewards I get, you might say it is a calling for me. I know the education and learning I gain on the job have deepened my life, and made me the caregiver I am today. Maybe that is why my friends refer to

me as a professional. As I spend time with other Maine P-ASA members, listening to them describe their work with adults and children with developmental disabilities and mental illness, I hear that they are professionals too.

What standards do others place on "professionalism" and direct care work? Does it depend on the specialized training? I have attended training that was shallow from lack of experience of the "teacher". I have also attended sessions that were so intense that it was difficult to internalize the information and use it. I have watched co-workers suffer the stress of poor training. Yes, we need to stress the importance of education, apprenticeship, and ongoing training to build and support quality, and professionalism, so that people can feel successful in this noble work. For centuries caregiving has been a part of the family function. Now that science has stretched the length of life with its joys and tragedies, people are living full lives with accommodations of medical and personal care, and are being helped by strangers, by employees. We need to take human care of this function. Human dignity and liability are at stake. This is why we can no longer see it as a "simple" role done by caring and available women. We must acknowledge the many skills the caregivers have acquired, pay for that skill, and not take them for granted, trivialize them or diminish the value of their work.

I have respect for the people I assist, and I work hard to show this in my work. Struggling to live on low wages, not having my own health needs covered because I don't have insurance, being treated as less than a "professional" makes me have to work hard to maintain my self-respect. I regain strength through the individual encounters I have with the people who depend on me every day. How does the public view me, and the thousands of caregivers and personal assistants working in Maine to support our elders and people with disabilities in the community?

I am a PCA. The people I assist, their families, the public, and my employer need me to be professional. They expect me to be professional. I would appreciate being valued for the work I do, for the difference I can make, and for viewing the work I do as a profession. Perhaps we need to start by getting others in the caring and support profession to acknowledge us, the front line caregivers, aides and assistants as part of the profession, as professionals.

2nd Annual Maine PASA Event Photos



Maine P-ASA member Kim Hale and Jennifer Gillespie, National Academy for State Health Policy and Technical Assistance for the Road Choice grant



Our Door Prize was made by one of our own Maine P-ASA supporters!



Maine P-ASA members met with guests from Florida, Connecticut, Vermont and Washington, DC, associations at the Maine P-ASA Pre-Event Dinner



Maine P-ASA member Trish Richard and presenters Patsy Harris and Anita Bolster (left to right)



Maine P-ASA members and presenters discuss the value of associations



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.

Volume 3, Number 1

February / March 2004

**“Our Stories” Coming Soon:
Maine PASA Welcomes Jocelyn Barrett**

In the last Maine PASA newsletter, we put out a call for stories. We hope to use these stories as a way of recognizing workers and demonstrating the value of their work. We are very pleased to announce that Maine PASA has started work on this project. Please welcome Jocelyn Barrett, Project Specialist for the Maine PASA Oral History Project.

Jocelyn will be working with Maine PASA members to complete a project for her 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. Once this was done, she was able to start her interviews. She is using the Feminist Oral History model, which uses a spoken story or conversation as the basis for the written story.

Please come to the member meetings on February 28th, March 13th or March 27th to meet Jocelyn. You may also contact her by calling the toll-free Maine PASA line, (800) 268-6612, or e-mailing her at jocelynbarrett@hotmail.com.

“I believe that everyone has a story to tell, and that there is someone, somewhere, who will connect to it and learn from it – but how many people ever get a chance in their busy lives to sit down and write their own story? Most people, even if they could, don't think that their experience is 'important' enough to tell. I am an oral historian because I believe that best and most important stories are the ones that might not get written for their very reasons. I feel privileged to be able to help people bring their stories into the open, to share with others so everyone can benefit and learn from them.”



Upcoming Meetings

February 28th, 10:00a-12:00p
University of Southern Maine
Portland Campus Center

March 13th, 10:00a-12:00p
Women, Work and Community
University of Maine-Augusta Campus Center

March 27th, 10:00a-12:00p
OHI Training Center in Brewer
242 State Street, Twin City Plaza

Members and interested guests invited!

For exact locations and directions,
call the Maine PASA toll-free numbers:
voice: (800) 268-6612
TTY: (800) 809-4501

Maine PASA Updates

Strategic Plan Proposed

Maine PASA's development over the last two years has been funded through a federal grant (U.S. Health and Human Services, Centers for Medicare and Medicaid Services, Real Choices Systems Change Grant, to the Maine Department of Human Services, Bureau of Medical Services, in partnership with the Muskie School of Public Service at the University of Southern Maine). A strategic plan has been proposed for Maine PASA to become a non-profit organization and to hold meetings to invite member involvement.

Maine PASA Board

The first step to becoming a non-profit organization is to form a board of directors. Maine PASA founding members will be joined by support members with expertise in organizational development and advocacy to oversee the development of by-laws and the Maine PASA operations and to complete the state application for non-profit and tax exempt status.

In The News

Maine Legislature decisions have an impact on workers

The Maine Legislature is making budget decisions and reviewing bills on issues that will have an impact on service providers, service recipients and workers in every sector of long term care. Some recent actions include:

- **The 2004 budget shortfall** of \$109 million Medicaid services was resolved through a number of funding reductions. The anticipated shortage of \$113-125 million for the next fiscal year 2004-2005 will necessitate more difficult decisions.
- **LD 1753:** An Act to Ensure the Quality and Safety in the Delivery of Personal Care Services. The bill to require personal care agencies to conduct criminal background checks on PC.As and other unlicensed assistive personnel before hiring was amended and passed.
- **LD 1791:** The bill to restore funding the certain nursing facilities and residential care facilities. Decision on the bill has been referred to the Appropriations Committee. Support for passage would restore cost of living adjustments and reimbursement reductions made in 2003.
- **LD 1090:** The bill to promote recruitment and retention of direct care workers in long term care was presented in a public hearing in January. This bill had the support but not the funding requested which would have supported a wage floor, or minimum, of \$8.35/hour for direct healthcare workers. The Resolve supports a sustained effort by the Direct Care Worker Coalition to review the wage and workforce issues. The Coalition will report to the Joint Standing Committee of the Legislation for Health and Human Services on January 15, 2005.

Personal Assistants Select MSEA-SEIU as their Union

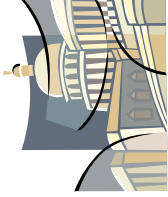
On January 5, MSEA-SEIU (Maine State Employees Association-Service Employees International Union) became the certified bargaining agent for over 1,000 Personal Assistants in Maine.

“The decision by Personal Assistants to choose MSEA-SEIU as their Union will help bring economic justice to a profession whose workers historically have earned low wages and been denied benefits even though they are paid with public funds... MSEA-SEIU members, friends and staff worked closely with both Personal Assistants and the people who use their services in this effort. MSEA-SEIU is now working with Alpha One, the employer, on a related legislative initiative. We’re supporting legislation to help both the people who use the services of Personal Assistants as well as the Personal Assistants themselves.”

Full report available: <http://www.mseaseiu.org/home.html> or contact Matt McDonald, MSEA, (207) 622-3151, (800) 452-8794, TTY (207) 621-1468.

Maine DD Council seeks board members

The Maine Developmental Disabilities Council (MDDC), also known as the DD Council, seeks consumer representation for Board of Directors. For more information, contact Andrew Roth-Wells at (207) 287-4221 or (800) 244-3990 (voice and TTY) or e-mail him at andrew.roth-wells@maine.gov.



Maine PASA Recognition

Maine PASA in the news

The January 2004 Issue Brief of the Better Jobs Better Care projects published by the Paraprofessional Healthcare Institute and the Institute for the Future of Aging Services is titled *Direct-Care Workers Speaking Out On Their Own Behalf*.

The article provides an important explanation of why associations like Maine PASA are important. And, Maine PASA founding member Trish Richard is quoted in the article! “In recent years, a growing number of groups have emerged to represent the interests of direct-care workers and to ensure that the value of their work is more widely recognized and appreciated. Worker associations help members develop their professional, leadership, and advocacy skills through education, networking, mentoring, and other types of support. Unlike unions, professional associations do not negotiate contracts with individual employers; rather they advocate for improvements in wages and working conditions across the sector.” (www.bjbc.org/content/docs/BJBCIssueBriefNo2.pdf)

The Maine PASA November newsletter, Vol 2, #6, article written by member Roberta Record, PCA, “Am I a Professional?” has been published in the national on-line newsletter of the National Clearinghouse on Direct Care Workforce, Voices from the Frontline: (http://www.directcareclearinghouse.org/voices_20.jsp) Congratulations, Roberta, and thank you for your contributions!

Maine PASA goes to Baltimore

Maine PASA members Julie Moulton, DSP and Roberta Record, PCA will be representing Maine PASA at the U.S. DHHS, Centers for Medicare and Medicaid Services, Annual Real Choice-Systems Change Conference, *Building Systems so that Money Follows the Person*, in Baltimore, MD, March 1-3. They will be serving on a panel at the pre-conference program on Workforce Recruitment and Retention and staffing the poster session for the full conference. For more information, visit: www.nashp.org/cmsconference2004.

This is YOUR newsletter! Give it YOUR voice!

Every thought about contributing
to the newsletter?



We need:
book reviews
poems and essays
personal stories
training opportunities
news bits

What do you want to share with other members?

Jobs, Jobs, Jobs

Health services jobs are at the top of the charts for job growth reported by the Maine Department of Labor. "Many of the fastest growing occupations will be in health care related jobs largely due to the rapid growth in the number of middle age and elderly people." The top 40 list for largest projected net job growth 2000-2010 includes: Personal and Home Care Aides (#1); Registered Nurses (#2); Home Health Aides (#3); Social & Human Services Assistants (#5); and Nursing Aides, Orderlies, Attendants (#19) (www.state.me.us/labor/lmis/pdf/MaineEmploymentOutlook.pdf).

Is this good news?

The biggest message here is to those people who are currently working as PCAs, HHAs, CNAs and Homemakers, Personal Assistants, PSSs, DSPs and other job titles that support elders and people with disabilities is that you are in demand! You are working in the top growth jobs and you are valuable! The State needs more people like you.

Where is the good job news?

If you are looking for a job that can make a difference in peoples' lives and does not require very much training to start than this news should tell you that you have your pick of jobs. But there is a catch. Many of the jobs will offer part-time hours, not include benefits like health insurance or sick and vacation time, offer wages less than \$9 per hour, and you will require that you have a reliable car. The work schedules, benefits and wage levels vary in these jobs depending on the employer and their client/consumer payment sources. If you have other sources of health care insurance coverage and income, and want a varied work schedule with flexibility, these jobs can be very rewarding.

If you are currently working in one of these jobs, Maine PASA wants to recognize you and the work you do. We appreciate the challenges you face and the contributions you make. We encourage you to seek support from your employers, your co-workers and the Association. We would also like to encourage you to stay in direct care and support work and recruit other people to these important jobs.

If you are looking for a meaningful job, Maine PASA encourages you to consider working in directcare, direct support and personal assistance. There are a variety of job titles, work settings, employers to consider. Maine PASA members would be glad to talk to you about their jobs and the work being done by the Association and others to raise the recognition, wages and benefits currently paid.

Where can you get more information?

For more information on training, contact the Maine Department of Labor's CareerCenters (www.mainecarecenter.com). Adult education and community colleges also offer a variety of training programs. Many employers provide training with employment.

For more information on job opportunities, check your local newspapers. Alpha One, an organization that supports independent living services for people with disabilities, can connect you with individuals with disabilities who want to hire personal assistants. You may contact them at (800) 640-7200 or visit their website at www.alpha-one.org. Stay tuned to www.mainepasas.org for future listing services for direct care and personal assistants!

Bonds and Boundaries: Thoughts on Caregiving & Professionalism

by Roberta Record, PCA

The world of caregiving has changed since more women moved into the workplace. In the past, women took care of family elders and friends with disabilities who needed assistance. Today, more elders are being taken care of by strangers. Questions surface for elders when an unrelated caregiver visits to be a part of their lives. Theft is the first concern. Is this person reliable, honest, warm-hearted? Do they have household skills, common sense, respect, and humor?

I find that elders have a hard time defining our roles as caregivers. We are either strangers or surrogate children, and there is no in between. An elder will say to me "You may be excused to go run and play." Another will tell me "You're a good kid." Male elders can look at a caregiver as a sex object. One man asked me if I would go to bed with him, another told me that if he was younger he would chase me, said to me in front of his wife. I find these remarks to be degrading. I have pondered this issue, and I've found that boundaries based on clarity of my role to be very important not only to protect the elder but also to protect myself from misunderstandings. This helps me to save precious energy to do our noble work.

The State of Maine attracts retirees and our resident baby boomers are aging. We will have a lot of elders who need assistance and care. The time has come to define who we are as caregivers. We are professional people visiting elders' homes to clean, shop, provide personal care, respite, companionship, or take elders to their appointments. We have to tap into our skills for empathetic listening, patience, respect for differences in opinions, politics, sports, religion, social studies, values and beliefs, storytelling, humor, wit, quick thinking. We need the judgment to know how best to care, assist or listen, and to know when bonds and boundaries are necessary - and how to balance them carefully. It is our profession.

The time has come to think about these roles as more than just an entry-level job. Hundreds of caregivers go to work daily to assist elders and people with disabilities in their homes. We can soften a harsh day, help someone get ready for days work, clean up a spill, supervise an emergency, appreciate the companionship of a cat, bring sunshine to a dull day, read labels, cook a meal, and save elder's money by price checking and clarifying confusion. It is all in a day's work for the caregiver. We are the new professionals to be recognized for working in our communities, helping elders and people with disabilities to be in their homes and our neighborhoods.



Check This Out

Creating Moments of Joy

by Jolene Brauckey

This book is a gold mine of information to make your day with an elder with Alzheimer's or dementia a little easier. Jolene's writings are a guide to possible opportunities to get into a moment of joy with your elder. Her insights help to change our focus and raise our appreciation of the people we care for. The information can be passed on to our elder's families to help them understand their loved one.



In a campaign speech given by Franklin Roosevelt on internationalism, Eleanor Roosevelt noted:

"We can lead the world by a great example...The Democratic program...is a plan of hope...We oppose money in politics, we oppose the private control of national finances...the treatment of human beings as commodities...the saloon-bossed city... (and) we oppose starvation wages..." [emphasis added]

(Eleanor Roosevelt: 1884-1933 by Blanche Wiesen Cook)



You're Invited to Join Us!

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

Maine PASA, P.O. Box 1881, Portland, ME 04104

Voice: (800) 268-6612, TTY: (207) 228-8440, Email: scalat@usm.maine.edu



Maine PASA
P. O. Box 1881
Portland, ME 04104



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.

Volume 3, Number 2

April/May 2004

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 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

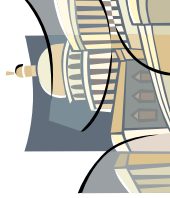
Topic: Working with High Physical Needs Consumers
 University of Maine-Augusta
 Women, Work & Community Conference Room

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.mainepasasa.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 www.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 affect the Alzheimer's, dementia, disabilities, and mental health community. ME/JAC 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 Benvenuto, facilitator, project coordinator and experienced board member

Board Members: Sherric 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 Benvenuto, 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 words, works, and actions.

Do it Anyway

by K. Keith (ISBN: 1930722214)

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



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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 snuff 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@botmail.com.





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Volume 3, Number 3

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).

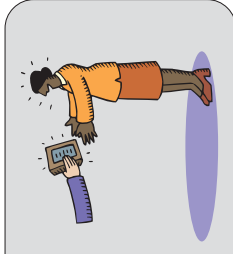


\$SCHOLAR\$HIP\$!

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.mecpep.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@dtcme.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.topica.com/maacs0uaa8yZZa97MUe/> and scroll down to pages 66-71.

Books To Share

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

By Barbara Ehrenreich

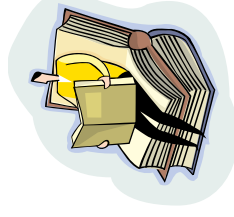
This is a work of research, but also a first-person account by the author who went undercover as a working American in four job settings. Two are of particular interest since one was in Maine (and was reportedly the hardest dollar she earned), working as a day maid. A second job of particular interest 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’Laughlin French)*

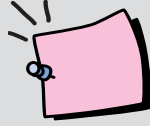
The Best Friends™ Approach to Alzheimer’s Care

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
P. O. Box 1881
Portland, ME 04104

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

by Jocelyn Barrett, writer, historian, Maine P/ASA 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 P/ASA 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 boards 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)

Special Insert

Maine PASA Newsletter

August 2004

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



Maine PASA, the organization working to recognize and build the direct care, direct support and personal assistance workforce through education, professional development and public awareness.

Volume 3, Number 4

November 2004

Making the Mission Clear

The organization that started as a grant proposal idea in 2002 has come a long way. Maine PASA is now incorporated as a non-profit organization in Maine and has applied for tax-exempt 501(c)(3) status. All of this growth has been serious business and the Board of Directors has risen to the occasion. Over the summer the Board members had to prepare Maine PASA for its transition from being a grant project to its new status befitting of the State of Maine and Internal Revenue titles. Serious discussions took place about what Maine PASA's mission should be. The Board is pleased to announce that with a little tweaking and polishing Maine PASA has a mission statement that meets a number of tests. In addition to expressing the importance of serving a public interest for quality care/support, the mission statement can be stated (with a little practice) "in the time it takes an elevator door to close". Picture this: Maine PASA's newly hired executive director has just met the Chief Medical Director and the Governor in the lobby. They notice the colorful brochure and attractive Maine PASA logo. What is Maine PASA they ask? Executive Director: "The mission of the Maine Personal Assistance Services Association is to build recognition and opportunity for the direct care, direct support, and personal assistance workforce through education, professional development and public awareness." (One of our newly printed brochures have been enclosed with this newsletter. You can also check out our website: www.MainePASA.org)

Great Reviews: Annual Event & Maine PASA Reception

On September 27th nearly 300 people gathered at the Augusta Civic Center for the Excellence in Long Term Care Conference. This was Maine's second annual event to honor and offer a day of education for Maine's direct care and direct support members of the long term care workforce and their co-workers. The program was sponsored by the Maine Long Term Care Ombudsman Program, the Maine Health Care Association and First Atlantic Corporation with co-sponsor support from Maine PASA, and the Home Care Alliance of Maine. The program evaluations were excellent and we can look forward to this being an annual event to recognize the important work performed by direct care and direct support staff. Special congratulations to this year's award nominees and recipients for the Excellence in Long Term Care Award. Linda Johnson, LPN TallPines Rehabilitation and Living Center; Phyllis Knox, CRMA, Victorian Villa; Barbara Lane, PCA, Area Home Care; Carol Lewis, CNA, CRMA, Monarch Center of Saco; Rose Ann Lowe, CNA, Seniors/Domestics Home Care Agency; Roberta Mathieu, CNA-M, Marshwood Nursing Care Center; Lynn Rainville, PCA, HomeCare for Maine (formerly Home Resources of Maine); Glen Theriault, CNA, Falmouth by the Sea; Patti Toothaker, CNA, Edgewood Rehabilitation and Living Center; Millie Wood, Social Services Director, Marshwood Manor.

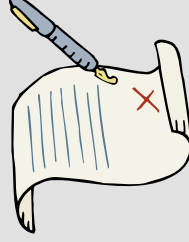
Best Friends™ Training Opportunities

Maine PASA has received funds to support members to attend the Best Friends™ Approach to Alzheimer's Care training program! This training addresses the needs of people with Alzheimer's and the importance of skills in the relationship between the caregiver and the client. Advanced registration is needed. Call Maine PASA to request funds to attend: (800) 268-6612.

- November 18th & 19th (2 6-hour sessions) in Caribou For more information, contact Nancy Sinclair at 498-6074.
- November 23rd & 30th (4 3-hour sessions) in Houlton For more information, contact Debbi Fitzpatrick at 532-6593.
- November 30th & December 9th (2 6-hour sessions) in Bangor For more information, contact Andy Finnegan at 947-4557 or Gerry Kearns Maklauf at 942-1152.
- To be announced: February training (1 8-hour) in Augusta For more information, contact Jan Halloran at 287-9233.

September 27th: Maine Long-Term Care Direct Care Appreciation Day

As a part of the "Excellence in Long Term Care" conference held on September 27th in Augusta, Governor John Baldacci proclaimed September 27th Maine Long-Term Care Direct Care Appreciation Day. Having this day to recognize the value of direct care, direct support and personal assistance



workforce is an honor for all workers and step toward our goal to raise public awareness of the value of the services our workforce provides every day.

Maine PASA Updates

Maine PASA Members Attend the DCA Conference

by Mike Jones

Recently, I was privileged to travel to our nation's capital to attend the annual Direct Care Alliance Conference. This was truly an awesome and inspiring event. There were people from many states in attendance, and we all had something in common. A few of the power points made during the conference - phrases that are few in words, but go a long way in expressing thoughts - are:

Nothing About Us Without Us! This means that we need to be actively involved with the process of promoting our profession and designing legislation and policies.

Keep the Passion Alive! Those of us who view what we do as a career, and not just a job, those of us who have a passion for what we do, need to keep that passion alive and work with those in power positions to form policy.

Help Us, Help You! Become actively involved with developing direct care to the level of professionalism that it deserves - that we deserved!

Maine PASA Member Attends CD PAS Work Group

by Joyce Gagnon

The Maine Legislature asked the Commissioners of Labor and Human Services to recommend strategies for improving services for the consumer-directed personal care assistance (CD PAS) and expanding care to include using surrogates when applicable. The group will present their findings to the Committee in January 2005.

The CD PAS study group participants include representatives from the following agencies and their consumer bases: Alpha One, Bureau of Rehabilitation, Elderly and Independence Organization, Home Resources of Maine, Human Services, Maine State Employee Union, and Retardation Organization. Each representative has brought their unique perspective and insights concerning programs, funding, regulations and differences between programs.

The CD PAS study group prepared a list of Foundational Principles as part of their review. The Principles cover such needs as a flexible and transparent system, seamless coordination of services, managing the person as opposed to just treating the symptoms, cost-efficiency, and living wages for direct care workers.

New Maine PASA Chapter Growing in Brewer

by Mike Jones

The seed from which the Brewer Chapter of Maine PASA grew was planted several months before its inception. After a number of meets with members for the "parent" group, the Brewer Chapter started to take shape.

At our October 16th meeting, many ideas were kicked around in regards to what the members of the Chapter would like to see in the way of programs. We'd love to hear your ideas! Visit the Events page on www.MainePASA.org to find times and dates of upcoming meetings.

Direct Care Worker Coalition

Created in 2002, the Coalition brought together for the first time state agencies, consumers, direct service workers and providers to improve working conditions for direct care and support workers through changes in public policy. The Coalition has more than twenty members, has developed an influential policy paper, promoted legislation, and conducted surveys. Organizational support is provided by the Maine Center for Economic Policy (MECEP). This Fall the Coalition is preparing a report to the Maine Legislature that will be issued on January 15th. This will be an opportunity for the administration, legislators and the public to hear about the status of worker wages and benefits and the impact of budget cuts on the long term care workforce in Maine. The Coalition mission is to promote policy and practices that respect and value direct care workers in order to sustain quality direct care in Maine. The Coalition has established three goals to focus its efforts.

1. Solidify the Coalition as a collaborative body with comprehensive representation to effectively make recommendations and advocate for a quality system of long term care and support services that is supported by a well-compensated, trained and respected workforce.
2. Provide research, analysis and recommendations to policy makers that advocate for this goal.
3. Promote workplace practices that support the direct care and support workforce.

Meetings are planned for November 17th and December 1st in Augusta. For more information contact Lisa Pohlmann, 622-7381 or contact Maine PASA regarding participation as a Maine PASA member: 1-800-268-6612.

National Updates

Legislation Introduced to Buoy Wages for

Direct Care Workers and Direct Support Professionals

For the first time, legislation has been introduced into Congress that would buoy wages for a group of our nation's quiet heroes – Direct Support Professionals. U.S. Representatives Lee Terry (R-NE) and Lois Capps (D-CA) brought to center-stage the *Direct Support Professional Fairness and Security Act of 2004 (H.R. 5197)*. This bipartisan legislation is designed to make funds available to states that would enable them to increase the inadequate wages paid to Direct Support Professionals (DSP) who, under the Medicaid program, provide supports to individuals with disabilities.

To learn more about this legislation, visit the American Network of Community Options and Resources (ANCOR) site at <http://www.ancor.org/2004>

**Check out the Maine PASA website
for upcoming events!
www.MainePASA.org/events.htm**

Excerpts from “What We Teach, What We Learn: Jennifer Grodewald’s Story”

by Jocelyn Barrett, writer, historian, Maine PASA member

“What We Teach, What We Learn: Jennifer Grodewald’s Story” is the third 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.

At age twenty-five, Jennifer Grodewald holds three jobs, often working seven days a week and up to ten hours a day. Jennifer makes it clear that working a packed schedule is a matter of choice and one she feels good about. She says, “Even in high school I was always the kid that said, ‘Oh, fifteen clubs? Not a problem.’ One year I don’t think I came home on the bus once, I was always there for something.” She has a bright, warm personality and a great sense of humor that shines through especially when she talks about Kristen, the twenty-eight year old woman she works with on weekends. Jennifer has facilitated Kristen’s independence in many ways, but the most important of which is that she treats her as a person and a friend, not as a client with a disability. It’s seems natural that Jennifer will assume that Kristen fully understands what’s happening and is fully capable, until and unless she communicates otherwise.



Jennifer Grodewald

The Best Part of the Job

On the weekends I work a 56 hour shift with Kristen. She lives in her own apartment but she has someone there with her all the time. Supported Living Facilitator is the official title the agency we work for gave us. I come in Friday nights at 11 o’clock, and I leave Monday morning at 7 am. I assist Kristen with pretty much every aspect of her life, though I always let her do what she can. For example, she can’t cook for herself, but she can be there with me if I need her to stir something. I have to hold it with her and help her do it. I can’t just say,

“Okay. We’re making brownies. Here, Kristen, here’s the bowl - stir it up for me and I’ll put it in the oven.”

I can’t ever really take a break. It’s not like I can go outside for a walk because I’m going crazy. The most I can do is to go in the other room for a little bit. Even then Kristen wants to make sure I’m okay. She’ll come in a few times to make sure I didn’t sneak out the window. If you’re doing retail in a store you can take half hour breaks and go somewhere else where there are no customers. With Kris, I don’t get to be completely off even when I’m asleep. If Kristen needs me in the middle of the night, I get up in the middle of the night. That’s just how it is. But we’re not considered on-call. If you were a doctor and you were on-call, you’d actually get paid for the hours that you’re asleep because they could wake you up at any time. But again, we’re not officially on-call, so we don’t get paid for all of it.

So many times I’ve said to myself, “I could leave here now and get a better paying job or work for a better agency, but then there wouldn’t be Kristen.” Kristen is the best part of my job and what it comes down to is that if I wouldn’t be working with her, I don’t want to do it.

My generation gets a lot of flack because people think we’re lazy, or we don’t understand what’s going on. I want to say to them, “You feel bad when we say, ‘Oh, you’re the older generation and you don’t understand us kids. Things were different when you were younger.’” You don’t like being labeled, so why do you label us? I show up, I never miss a shift; you can count the number of times I’ve called out on one hand. Yet you constantly say “These young people...”

In this line of work you make lasting relationships, and some people aren’t ready for those relationships; it has nothing to do with age. The people you help are very dependant upon you. You can’t just decide that it’s a beautiful day and you don’t want to go in. I can’t call and tell Kristen I’m not coming because I feel like going to the beach today. She’d say, “Well, you can’t do that because I need somebody to come make me breakfast. If you don’t come, I don’t get to eat.”

(cont’d)

Remember to say Thank You!
 November is National Family Caregivers Month,
 National Home Care Month and National Hospice Month!

Patience

With Kristen I learn a lot about patience. I've been told in the past that I'm a patient person but I never felt it. People would say, "Oh, you must be patient to teach thirty kids in a classroom at the same time. You don't get upset, you don't yell at them." I know how to hold my tongue but that doesn't mean I'm patient. I don't feel patient even though I am smiling and look calm.

I think with Kristen I truly understand what patience is. It might be easy for you or me to say, "Can you pass the juice?" Because she can't actually get that out, she has to have a lot of patience to get her point across and have people address her needs. Sometimes I'll say, "Oh Kristen, I'm not feeling all that patient with you today." She just kind of smiles like, "I don't care, because I can still be patient with you. I'll let you mess up as many times as you want; just remember, in the end you're going to have to get it right." It's hard to find someone nowadays who is accepting of everyone, but I don't think there is anyone to whom Kristen would say, "No, you can't come into my house because I don't like you." I think a lot of times we judge people by the way they look and the way they act. With Kristen that's all gone. She doesn't care.



Jennifer Grodewald, Kristen and Kristen's mother

The Work We Do Together

I had to do a NAPPi training for work – Non Abusive Physical and Psychological Intervention. It basically explained to me how to defend myself if Kristen were to come at me with a steak knife. I sat through the whole training thinking, "Kristen can't even hold a steak knife." The worst thing that will happen is that if we're having a really bad day and I do something that really

irritates her, she might pinch me. I say, "Kristen, don't do that." If she does it again I say, "Kristen, don't do that" and I hold her hand because she can't pinch me while I'm holding her hand, so she stops. We were sitting in this training trying to figure out how to get rid of behaviors, and that's fine. But we also have to figure out why she's behaving like this. There has to be a reason, right?

Kristen has a habit of going into the kitchen and picking up her cup, and when she realizes there's nothing in it to drink she just tosses it. It's her way of asking for a drink. One day I figured out it's so much easier for me to pour a little bit of juice in the bottom of her cup and leave it in the refrigerator and say, "Alright. It's right there. You know how to get it, so don't go throwing cups across the room." She can go in and drink when she's thirsty and put it back. I only leave a few mouthfuls, because sometimes she can't hold it and she'll just drop it. I figured it's easier to clean up the mess after and let her have some independence than making it so that every time she wants a drink she has to come and drag me to the kitchen.

Think to yourself, "What do I have to do today?" Imagine having to do laundry, dishes, go to the bank, go grocery shopping. Sometimes I'll see Kristen just stand at the bottom of a flight of stairs and know she's saying to herself, "Alright, I need to get up that flight of stairs but first let me look at it. Okay, there's nothing in my way. Now, what I'm going to do is I'm going to hold on to the railing and take one step, then go from there." She has to make a whole plan to go up a flight of stairs, and she has to do it every time. We take so much for granted. She has to overcome so much more than us, yet people think that she's somehow worth less because she can't do certain things. They think because she doesn't hold a steady job and doesn't have her own income she's a lower member of society, or not deserving some things because she doesn't work for them. They can't understand, because they don't see all the work we do together every day.



Jennifer and Kristen

Excerpts from “Compassion and Insight: Mike Jones’ Story”

by Jocelyn Barrett, writer, historian, Maine PASA member

“Compassion and Insight: Mike Jones’ Story” is the fourth 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.

Mike Jones is a Certified Nurse’s Assistant (CNA) who has been working in the Bangor area for more than eleven years. In his time as a CNA, he has taken advantage of every training opportunity offered to him and has also been qualified as a Personal Support Specialist, a Certified Hospice Aide, a Certified Residential Medication Assistant, and a Mental Health Rehab Tech among others. As he says, he has a “string of an alphabet” after his name that’s proof of his willingness to accept a new challenge and to learn more about his work. He’s been doing home-based care in Maine for the past five years. He believes in empathy and compassion, not sympathy. As he says, he doesn’t “sugar-coat” when he goes into a consumer’s home, and he doesn’t need to. His easygoing nature and genuine concern for the consumers he works with make him a great Personal Support Specialist.



Mike Jones

Finding a Place in Homecare

Over the years, I have sometimes had to try harder to do better than my female coworkers. Mostly we think of men as doctors, therapists – you might find them in the hospitals, as orderlies or things like that. To have men doing home healthcare, real hands-on stuff like housework, they think that there’s got to be something a little bit “wrong.” People will ask me, “Well, do you know how to give a bath?” I’ve had the same training as everyone else. “Well, doesn’t a woman’s body bother you?” No more so than a man’s does. A body is a body. All women are built the same, and all men are built the same.

There was this one couple I worked with that were in their early nineties when I started with them. They had been married for 74 years at the time of the husband’s death. When I first started there, they were very leery about having a man helping them. She watched me like a hawk. It helps some that the cooking I do is of the old fashion style – good old home cooking. I don’t just

take something out of the freezer, pop it into the microwave, toss it onto the table and call it lunch. I hadn’t been working there very long when she started making these bread hints, “Gee, I wish somebody would make me some chocolate chip cookies. I haven’t had a good homemade cookie in a long time.” I was thinking “I’m only here for two hours and all this other stuff needs to be done.” Yet, I really wanted to do it for her. The answer? I went to the store; got some Betty Crocker pouch mixes, added an egg, a stick of butter, cooked them off and she had homemade chocolate chip cookies. She was so happy, so appreciative. I made those cookies at least once a week for over two years.

Daily Insights

I did Hospice work for a while. My philosophy while working in Hospice was that I was not allowing people to die with dignity, but rather to live with dignity until they died. I had a Hospice client once that had a very profound effect on me. At sixty years old, she was diagnosed with terminal lung cancer. She was a college professor and had taught overseas at a number of universities; a very interesting person. I got called and I was putting in about twenty hours a week with her. She had 24/7 coverage by CNAs and RNs. I was involved with her care, hand in hand, with the RNs. I helped them perform duties that CNAs usually don’t get involved with. The woman had gone through a procedure of deadening the nerves in her mid-back that rendered her legs useless. The procedure required that she lie on her back, legs elevated, for a number of hours. Because of the procedure and her compromised system, within days she developed a pressure sore on the base of her spine. She had no healing powers. I had to help the RN treat it simply because she couldn’t turn the lady onto her side or stomach to treat her back, and the sore was just bigger then what she could handle alone. She needed an extra set of hands. I got into a lot of situations with her and other Hospice clients that I normally wouldn’t as a CNA.

This client was a very private person. I don’t know if it was something she sensed about me, but she opened up to me a lot more then she did with the others. Something she had been ready to take to the grave with her, that she confided in me, really hit home. Because of the lifestyle she had determined to be right for her, she had been rejected by her adoptive father. This really impacted me because she and I shared that aspect of life. She had only one other living relative that she knew about, and was there dying alone. I thought, “This could be me in another twenty years.” That hit really close to home.

(cont’d)

The last time I saw her, I was being relieved by the next worker. I'd already been there for my shift. She was beyond speech at this time, but she was still alert. I walked up beside her bed, the other direction and looked at me. She didn't move her lips, but she had a look in her eyes that said she knew this was the end. She looked right at me and with her eyes said "Thank you." I picked her hand up, kissed it, and said, "Little Sister, I'll see you the next time the circus is in town." I left, and twenty minutes later, I got a call from the other CNA telling me that she had died.

I stopped doing Hospice a little while after that. That was a once in a lifetime situation. That situation rattled me to my foundations and I don't know how many of those I would be willing to take. When you're sitting there for hours and you're discussing politics, you're discussing education, music, life in general, world events, you're reading the newspaper to her, you're fixing meals, feeding her, trying to get her to drink – it brings you into such a bond with that person that you bend and you're almost a part of each other. And I knew she was going to die, but I didn't expect that feeling to happen. But she looked at me with her eyes and said thank you and that just rattled me.



Mike and Eric

Being Challenged

Right now I've got eight clients. Most of them are more "housekeeping" type personal support. I do some housework, laundry, grocery shopping, that sort of thing. For most of them, there's not really any hands-on direct care. However, there's this one guy, Eric, who's wheelchair bound and almost total care. I spend an average of twenty-one hours a week with him. Eric just about challenges every part of my ten years of training and experience. He is total care, which means I bathe him, I dress him, and feed him. I also assist him with medications. I sweep and mop his floors, I cook whatever he wants for meals, I do up the dishes; I even empty and clean the cat's box. I help him keep his appointments straight, and remind him when he has something coming up. Eric discusses problems with his girlfriend with me; he discusses problems with his family with me. Sometimes I'm dealing with his depression, anxiety, things that I have learned about in the past. So, it all plays in – CNA, PCA, homemaker,

mental health worker, medications. His is a challenging situation, yet he is a joy to be with because when his mood is up there, he has a laugh on him that would make a rock laugh.

This job is not just a matter of sweeping floors, doing dishes and washing somebody's behind. An RN or an LPN or a therapist comes in for a short visit for a very specific purpose. Of course, they would listen if a client had something to say, but they just don't have the time to stand there and get into it. As PCAs we don't deal on that level. We go into that home for general purposes and that means you can get hit with anything going and you have to be ready for it.

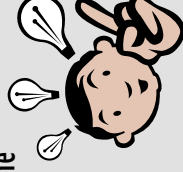
I'm very pleased that they have changed our designation from Personal Care Attendant to Personal Support Specialist. If we are doing our job right, we provide support in a wide range of issues and situations, and we do become specialists. We work on a very personal basis. Do you know how many people I meet who ask, in casual conversation, what I do for work? When I tell them that I am a Personal Care Attendant, a Personal Support Specialist, they sort of wrinkle their noses and say something like, "Oh, you go in and give bathes and sweep floors, and stuff like that." Then they will add "I could never do that." Well, if the general public can't do that, doesn't that make me a specialist because I do it effectively, and continue to do it? That needs to be recognized.



Mike and Eric

Don't forget to check out the complete versions of the stories on the Maine PASA website!

Go to www.MainePASA.org and click on "Our Stories"!



The Votes Are In!

Maine PASA Wish List Results

The Maine PASA display table at the Excellence in Long-Term Care Conference asked the question: *Oh wouldn't it be nice if we could have...* Conference attendees were asked to place stickers marked 1, 2 and 3 to name their top three wishes. Check out the results!

Increased Wages (total votes: 85)

- #1 selection: 54
- #2 selection: 21
- #3 selection: 10

Enough Staff (total votes: 66)

- #1 selection: 34
- #2 selection: 21
- #3 selection: 12

Affordable Health Insurance (total votes: 57)

- #1 selection: 17
- #2 selection: 21
- #3 selection: 19

Respect & Recognition (total votes: 41)

- #1 selection: 8
- #2 selection: 17
- #3 selection: 16

Training & Education Programs (total votes: 31)

- #1 selection: 5
- #2 selection: 14
- #3 selection: 12

Career Advancement Opportunities (total votes: 29)

- #1 selection: 10
- #2 selection: 8
- #3 selection: 11

Stable Work Hours (total votes: 14)

- #1 selection: 4
- #2 selection: 4
- #3 selection: 6

Help with Child Care (total votes: 8)

- #1 selection: 1
- #2 selection: 2
- #3 selection: 5

Health Insurance: Are You Looking for Coverage?

The headline news across the country is that thousands of people do not have health insurance. In Maine the count is 130,000. What do they do when they get sick? There are many direct care workers and personal assistants in Maine who could answer this question. Maine PASA surveys tell us that health insurance is high on the wish list, especially for home health and care aides and personal assistants. Between part-time work schedules that make them ineligible for employer benefits (with few even offering the option) and hourly wages between \$7.00 and \$10.00, the chances of finding affordable insurance and health care services are very slim.

If you are in this situation please read on...

Dirigo Health is offering a new health care coverage choice in Maine for small businesses, self-employed, and individuals without access to job-based coverage. The DirigoChoice Program may be able to offer you affordable health insurance. Check these sources for more information:

1. Are you employed by a small business/agency? If so, ask your employer to call Anthem Blue Cross/Blue Shield to get information and rate quotes. DirigoChoice has a good plan for low wage earners that will help you pay for many of the out-of-pocket costs. Currently, you must go through your employer and fill out the necessary paperwork to find out how you can qualify. Please be aware that there is a cost to your employer to participate, but encourage them to call Anthem to find out how much it really is and tell them how important the coverage is to you. The Anthem BCBS number for small businesses is (800) 541-4251.
2. If your employer does not enroll in DirigoChoice or you are not eligible because you work too few hours, consider this... Starting in February, the State will accept 2,200 individual's applications for DirigoChoice coverage. This insurance plan with the wellness incentives will include assistance for low wage earners. The catch is that you must get ready and get in line for the opening day. You will need to have your household information ready for the application day. For more information: phone: (207) 287-9900, TTY: (207) 287-4344, email: DHA@Maine.gov, website: www.dirigohealth.maine.gov.
3. Nearly 20,000 children and adults are eligible for MaineCare full benefit coverage but do not enroll. To get more information, call the Department of Human Services toll-free at (877)KIDS-NOW (877-543-7669), TTY (800) 965-7476.



YOU Can Make a Difference!

Maine PASA is looking for an Executive Director! Check out the back of this newsletter for more information!

Contacts that can help you learn more:

- Consumers for Affordable Health Care (800) 965-7476 or <http://www.maineahc.org/>
- Covering Kids & Families Hotline (800) 965-7575
- Artists' Health Insurance Resource Center www.ahirc.org and click on Maine on the map

Job Announcement: Maine PASA Executive Director

Maine PASA seeks a person with the knowledge and experience of managing a growing non-profit organization. The ideal candidate will demonstrate insights into Maine PASA's mission and its members and the skills to lead and manage the organization.

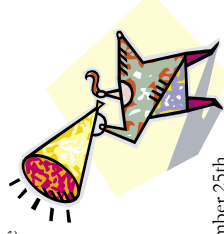
The Executive Director will assist this newly formed organization to accomplish its important mission to build recognition and opportunities for the Maine direct care, direct support and personal assistance workforce. Maine PASA is an incorporated non-profit organization that currently serves a statewide membership of nearly 500 and is affiliated with numerous state and national initiatives dedicated to building quality work and ensuring quality services for elders and people with disabilities. (See www.maine-pasa.org to view the organization and the full job description). The Executive Director performs a wide range of administrative activities related to the operation and management of Maine PASA programs and budget and reports to the Board of

Directors. The position is currently half time, involves a flexible schedule with occasional evening and weekend meetings in Augusta, Bangor, Mid coast and Portland area.

For the full job description and a listing of requested qualifications, go to www.MainePASA.org.

Please submit a cover letter & resume with contact information for 3 references to:

**Search Committee
Maine PASA
P.O. Box 1881
Portland, ME 04014**



Review of resumes will begin November 25th and continue until the position is filled.



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.

Address: P.O. Box 1881, Portland, ME 04104
Voice: (800) 268-6612
TTY: (207) 228-8440 or (800) 809-4501
Email: scala@usm.maine.edu
Website: www.maine-pasa.org



Maine PASA
P. O. Box 1881
Portland, ME 04104

Special Insert

Maine P-ASA Newsletter

November 2004



Maine P-ASA's Chapter in Brewer
Left to right: Wuzzy Cox, Maria Bowden, Mike Jones



Maine P-ASA display, Excellence in Long-Term Care
Conference, Augusta Civic Center
Jennifer Gillespie, Maine P-ASA Board of Directors
member, checks in. (Note our Survey Board to the left.
Attendees made their wishes known!
See "The Votes Are In!" on page 7.)



Maine P-ASA Reception, Excellence in Long-Term Care
Conference, Augusta Civic Center
Julie Moulton, Susan Tucker and Mike Jones tell about
the DCA Conference and visit to Washington.



Mike Jones, Susan Tucker and Elise Scala staff the Maine
P-ASA poster session at the DCA Conference along with
many other Associations from across the country.

Special Insert

Maine PASA Newsletter

November 2004



*Direct Care Alliance Conference
Washington, DC, September 2004
Susan Tucker joins other direct care and
support workers from across the country
to connect and celebrate their work.*



*Direct Care Alliance Conference, Washington, DC, September 2004
Maine PASA debuts the Our Stories display.
Left to right: Mike Jones, Elise Scala, Susan Tucker,
Jocelyn Barrett, Gail Benvenutta*



*Direct Care Alliance Conference
Washington, DC, September 2004
Maine PASA goes to Washington!
On our way to Tom Allen and Olympia Snowe's offices.
Susan Tucker and Julie Moulton tell about
Maine PASA's mission.*



The mission of Maine PASA is to build recognition and opportunity for the direct care, direct support and personal assistance workforce through education, professional development and public awareness.

Volume 4, Number 1

March 2005

Maine PASA Board Appoints an Executive Director

The Maine PASA Board of Directors is pleased to announce the appointment of Roy Gedat to the position of Executive Director. The position was advertised in December and recruited many excellent candidates. Roy was selected for his extensive experience in managing a non-profit organization in Maine as well as his first hand experience in direct services. Roy served as the director of the Child Health Center in Norway, Maine for 18 years and was very active with fundraising for Big Brothers Big Sisters programs. He has also been a board member for other organizations. Roy is familiar with direct services through part-time employment in a residential home for people with disabilities, through his agency work, and through his Master's degree in social work. Roy comes to Maine PASA with great recommendations and a track record of collaboration across many service, business and policy groups. The Norway community knows Roy from his November run for the Maine House in District 95. Roy brings terrific experience and energy and will be instrumental in leading the organization and the Board to ensure Maine PASA's mission and contributions to workforce developments in the state. Roy has been busy talking to Maine PASA members and getting to know the grants and projects, and the mission of Maine PASA. Drop him a note and set up a time to talk about Maine PASA and direct services in Maine. You can reach him by e-mail (rggedat@exploremaine.com), by calling his direct line (207-890-0773), or by calling the Maine PASA toll-free number (800-268-6612).



Roy Gedat
Maine PASA Executive Director

Maine PASA Gets Tax Exempt Status

The U.S. Internal Revenue Service approved Maine PASA's application to become a 501c(3) organization in January 2005. This is another important milestone for Maine PASA and follows the serious work done by the Board of Directors to write a mission statement and business plan that tells how the organization will serve its members and the general public. Being approved to be a tax exempt 501c(3) and an incorporated non-profit organization in Maine are important demonstrations of Maine PASA's status and suitability to serve its members, affiliates and funders. This is a responsibility and a trust that the Board and Executive Director will carry out. Maine PASA welcomes contributions, including financial donations for designated support activities. These contributions are now tax deductible! Please contact Roy Gedat, Executive Director, for more information.



Maine PASA Has A New Mailing Address!

P.O. Box 710
Norway, ME 04268
Portland mail will be forwarded.

Health Insurance Outreach Help Needed

Maine PASA is concerned about health care coverage for direct care, direct support staff and personal assistants. Our members have told us this is one of their top issues and that it can make the difference between staying in this line of work and leaving to find a job with benefits. We need to find and keep good people in these jobs! And, we know that this is only going to happen if we improve the jobs. One way we can do this is to make sure employers (agencies and consumers) and their direct care and personal assistants have good information and know what the benefit options and costs are.

Maine PASA is working with Consumers for Affordable Health Care and the Health Care for Health Care Workers Initiative, a national effort sponsored by the Paraprofessional Health Care Institute to offer information and support. Employers watch your mail for announcements of meetings in your areas and the Small Business Newsletter with information about DirigoChoice. Maine PASA members: You can help! We are recruiting direct care employees, direct support professionals and personal assistants to attend trainings and assist with outreach that will help other workers to find health coverage. Call Elise 228-8423, or Roy (207-890-0773 or 800-268-6612) to find out how you can help.

Checking In With Members

Many Maine PASA members received phone calls from the Board members, the Chapter leaders or Jocelyn Barrett. Forty people answered our calls and our questions. This was a great chance for us to make contact and get feedback on how we're doing.

What did we learn?

Most people read and enjoy the newsletter (hooray!), most people have not read the website, and many have not seen the Our Stories series. This is helpful for us to know. If you or your employer has access to the Internet, check the website together: www.maine-pasa.org. We think you will be impressed with what Maine - and your Association - is offering!

And, we heard that you are very busy working and don't have time to attend events. We also heard that you have concerns about your jobs and co-workers in direct services.

Members' concerns generally fell into the following areas:

Raising Public Awareness

- "We're getting bad press from dishonest people, we need good stories, too."
- "We need to give people an overall view of mental illness, provide education for people in the community."

Employee Recognition and Support

- "Give everyone an opportunity to speak, 'once around the table.'"
- "We do not get recognized for the good work we do."
- "I want to be with others doing the same work to discuss and have fun."
- "A happy employee is a good employee; we have to be valued."
- "It's not always about the wages. People that do the work should get more support and understanding so they can do their job better."

Health Insurance

- "It's awful to be in healthcare and not have health insurance."
- "Healthcare is the biggest issue. It makes it hard to find young workers who want to stay in this field."
- "I am approaching retirement and would like to cut back to part time, but I'll lose my health insurance and just can't afford that."

Low Wages

- "We need higher wages, I make less now than I did when working at a factory in the 70s. But if we raise our wages too high, will we have to charge poor clients more for services?"
- "Having been promoted to CRMA, with more responsibility should come higher wages and more respect but the pay scale is so low at the private facility where I work."
- "We need to have good pay to get people into this job."

Long Hours/Inconsistent Schedules

- "Our schedules are too inconsistent. I wish we had reliable, steady schedules to work."

Conflict Resolution

- "We should have support groups. 90 % of the problems are with co-workers. We need time together."

Burnout

- "I'm concerned about people who were fired up about their jobs but have changed. What can we do about the burnout I see in others?"
- "I'd like someone to talk to on rough days."
- "I need someone to listen to me when I have lost my patience, or am feeling degraded by the environment or person I'm working with."

Problems at the Legislative Level

- "The State and Government are not doing well to provide and pay the bills."
- "This is not entry level work and it is not an area to save state and federal money when they are downsizing budgets."

Lack of Training/Outdated Training

- "We should have refresher courses in CNA work, one day seminars to teach new tricks of the trade."
- "We need good training by well qualified people."
- "We need classes on Alzheimer's because more and more consumers are affected."

Trouble with Management

- "If you don't voice your needs, you're just punching a clock."
- "I feel that management is very insensitive and unfair to in-home workers at my agency."
- "Accessibility to supervisors is a problem."

Relationships with Consumers and Consumer Family Members

- "Family members can be tough."

Finding and Keeping Good Workers

- "This is more than just a job."

How do I contact my Representative or Senator?

Maine House of Representatives in-state toll-free line:
800-423-2900

Maine Senate in-state toll-free message line:
800-423-6900

To locate any state official, visit:
<http://www.maine.gov/portal/government/officials.html>

Excerpts from ‘Someone to Care for Caregivers: Karen Bragg’s Story’

by Jocelyn Barrett, writer, historian, Maine PASA member

“Someone to Care for Caregivers: Karen Bragg’s Story” is the fifth 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.

Karen Bragg works as a Caregiver Companion for Elder Independence of Maine (EIM). For the Caregiver Companion Project three EIM employees have been trained as Alzheimer’s specialists, working in the homes of consumers who receive support services. The Caregiver Companion’s role is to work one on one with family members who provide unpaid care for their loved ones. Karen is a compassionate, thoughtful person who is sensitive to the needs of those she meets with. Her own experience as a family caregiver is what led her down the path to this “dream job,” and her genuine compassion and insight into the situation for family caregivers is what makes her excellent at it.

Better Relationships, Better Jobs

I’m an Alzheimer’s Specialist and I work with the Caregiver Companion program at Elder Independence of Maine. EIM connects people in Maine with home care services, coordinates with families to have PCAs or CNAs come into the home to care for a loved one. When the home care services are being arranged for a consumer with Alzheimer’s or dementia, they call me. I go in and work with the primary family caregiver in the home. I give the caregiver a call and ask how they are doing. I say, “How are you doing?” Family caregivers are used to everyone asking, “How’s your husband doing? How are services going for him?” No one asks the caregiver if she’s doing all right. There’s so much going on that the caregiver is forgotten about.

My job is to try to make the family caregiver’s job easier in any way I can. Often, since there are new PCAs assigned to the family through EIM, I end up acting as a mediator between the family caregivers and the professional caregivers they have coming into their homes. This is a new experience for the family caregiver, it can be difficult for them to adapt and sometimes there is tension there. I understand how tense the relationship between family and professional caregivers can be because I was a family caregiver for five years.

Being a caregiver for my grandmother changed my whole direction. I didn’t finish RN school and I don’t regret that at all. I started a home care agency that was run on my philosophies about creating a relationship with family caregivers and with clients. I knew some really good PCAs in the area and recruited some great people. Before we even started I asked them, “Do you know how it felt for me to see PCAs come into my home and go right past my grandmother and never say a word to her, or me? They weren’t treating her like a person, and that made me feel even worse because I couldn’t do anything about it. I needed them there because I needed help.” It was an important awareness, and that awareness helped good PCAs do an even better

job. I really believe that caregivers, clients and PCAs all have to be remembered and respected for things to work out.



Best Friends™

I often teach the Best Friends™ approach when I’m working with family caregivers. Beyond lending a sympathetic ear or getting a caregiver out of the house for a while, I find that talking them about the Best Friends™ approach can really help them to have better interactions with their loved ones every day. This approach can help people to come to terms with what’s happening. What if your husband or your grandmother was the rock of your family, someone you always turned to, someone you could always cry to? It’s so hard when you always went to your mom or you always went to your dad or grandparents, you always turned to your husband and suddenly that person is still there, but that source of support is gone. It’s a huge loss and they’re grieving that.

Usually I don’t even meet the client with dementia. I work solely with the caregiver, and try to get her out of the home so she can have a break. If the caregiver wants a better understanding of the Best Friends™ approach, I will actually go in for an afternoon and meet the client and try to role model to help teach the caregiver how it’s done. Sometimes Jack is sitting here and he says it’s Friday and the wife is frustrated. “It’s Thursday, honey. You know it’s Thursday.” I gently introduce a different idea, which is to accept that Jack really believes it’s Friday and by trying to convince him it’s not, it may just confuse him and make things tenser. What if we accepted that and tried to let it go? I smile and say, “Yes it’s Friday, Jack, it is. And it’s a beautiful Friday.” I

just let it go, then I redirect. "Your hair looks great" or "Your sweater is so pretty. Are you having a good day?" If the caregiver can let it go and move beyond it, it makes the client more peaceful and can make their interactions much smoother.

Sometimes I meet a caregiver and I know it's not a good situation anymore. For the five years I cared for my grandmother I had nobody to turn to. My husband would say over and over, "You can't do this anymore." The more people would say, "You can't do it," the more I hid things. It would get really bad and I'd be totally burnt out and think "Oh, god, I don't want to let my husband know that I'm having a really hard time." I didn't want to stop being a caregiver to my grandmother. I was the only one who could say that my grandmother needed to go into a nursing home. Caregivers hide a lot; they cover a lot of pain because they don't want to have people say, "You can't do this anymore." What I say to them is, "You can do it for as long as you feel that you are able, but you're the only one who can say, 'Now's the time. It's not going to be your daughters, not going to be your sons, it's not even going to be the doctor.'"



Giving 100% Every Day

May 6th of this past year, I had a life-threatening illness and almost died. In some ways, I think I have changed. Whenever I start to get uptight or anxious, a wonderful calmness comes over me. People that know me well have commented that they have noticed a change. When I sit and talk to caregivers facing stress in their lives, I think I am better able to calm and reassure them now. There is laughter and sometimes tears. We talk about memories and how important our memories are. Best Friends™ helps with those memories because if a caregiver can accept that their loved one can't get their memories back, they can at least live peacefully for the rest of their days and make new memories together that the caregiver can keep. I talk to caregivers about memories because each day they spend with their loved one is very precious. I feel like I got the inside scoop on something, you know?

I have lost quite a few caregivers because once the consumer with dementia or Alzheimer's dies, we have to end our work with the caregiver. I had a funeral director tell me something once, and it really helped me when I've lost someone to dying. He said, "Every family that walks in gets 100% of me. I'm there for them 100%. But you know what? There's always another family who's

going to need me. And I'm going to give them 100% of me as well." So I always have to figure out, "What is 100%?" I think it's just giving your time to somebody and letting them know they matter, and that's what I do. I give 100%, but I always know that there is another caregiver and I need to be 100% again for tomorrow.

Special Thanks to Jocelyn Barrett

The Our Stories project is one year old. During this time, Jocelyn Barrett talked to Maine PASA members and got to know some very impressive direct care and direct support workers and personal assistants. Seven people offered to be interviewed and share their stories with Jocelyn and with us. The Maine PASA website has all seven stories for you to read. This newsletter features "Someone to Care for the Caregivers: Karen Bragg's Story," and coincides with our announcement of funds to support Maine PASA members to attend Best Friends™ training. We have two other wonderful stories to share with you in future newsletters, "An Open and Loving Heart: Susan Tucker's Story" and "Thriving on Challenges: Karen Farrington's Story."

While completing the interviews and multiple drafts Jocelyn was very busy helping Maine PASA with member development. Maine PASA is very appreciative of Jocelyn's fine work to develop and publish the Our Stories project and her outreach to members. While her employment with Maine PASA comes to an end, her membership will continue. The Our Stories series is reaching many people and is an important demonstration of Maine PASA's work and purpose. Thank you, Jocelyn, for giving us a way to be heard and understood.

We also thank Priscilla deBree, Studio 148, the photographer, who so beautifully put a face to the work and workers described in these stories.

The Our Stories Project is finishing up. I started last year at this time, and could never have imagined what a success it would become. We've completed seven stories, each told in a distinct voice. These are stories that need to be heard. I'm amazed when I think that Our Stories shares only seven out of all of your voices. I could choose any of Maine PASA's members and you would have a story that is just as important as those in Our Stories.

Even though Our Stories is coming to an end, I hope that the Maine PASA newsletter can be a place for more of your ideas and stories to be shared. I have enjoyed getting to know you. One thing that I've learned in working this past year is that the heart of Maine PASA is its members, and it's what you bring to the organization that makes us what we are.

Jocelyn Barrett, February 2005

Maine Updates

State House Activities that Affect Maine PASA Members

by Roy Gault

The Legislature is in session and the Governor recently delivered another budget that features Medicaid cuts and government restructuring that concern direct service staff who work in homes, institutions and smaller residential living facilities. As details emerge on the impact these cuts will have on elders, people with disabilities, and children in residential care, another controversy is heating up in response to the long planned merger of DHS and BDS.

Home-based and residential services to former BDS clients will be particularly hard hit by funding reductions as attempts are made to move clients into less restrictive and less "expensive" methods of care. Elders are said to be "held harmless" in the budget but the details in changes to MaineCare have yet to emerge clearly.

While advocates attempt to preserve and maintain current service levels a strong effort is being made to shore up and even increase funding levels for homemaker and other home-based services with waiting lists.

The Commissioner of the new super-agency DHHIS (Department of Health and Human Services) has begun to reveal the structure, which is organized around common intake and interdisciplinary case management of individuals and families. The former bureau for Maine's elderly is nowhere to be found in the new organizational chart and its functions are grouped together with the developmentally disabled into a new office of Elder & Adult Behavioral and Developmental Services.

Advocates and providers of senior services are fighting this effort to combine elder services, long-term care with adult mental health and retardation programs. One bill now before the Legislature directs the creation of a strong bureau-level aging office. There are also many huge budget savings envisioned for efficiencies that will reduce costs of residential care that are very concerning to clients, their families and providers.

Everyone agrees that the creation of the new Department offers a historic opportunity to improve and enhance the complex and diverse service system where PASA members work.

Notice: Just last year Maine established unemployment compensation coverage for part-time workers. The continuation of this coverage is being debated. For more information and to voice your support, you can contact Crystal Bond or Chris Rusnov at Maine Equal Justice at (toll-free) 866-626-7059, x 205.

Watching Medicaid in Maine

Because many people receiving long term care in Maine rely on Federal and State Medicaid funds direct care and direct support staff and personal assistants can expect to feel the impact of cuts and changes. Maine PASA recommends that members listen and watch, and call us with what you're experiencing on the front lines of caring. Maine Center for Economic Policy (www.mcecp.org) and American Network of Community Options and Resources (ANCOR.org) are great resources for budget news.

Direct Care Worker Coalition Makes A Presentation to the State Administration in December

Coalition members presented a summary of the direct care worker employment situation to key members of the state administration, including Irish Riley, Rebecca Wyke, Catherine Cobb and Pat Ende. Maine PASA members and long-time direct service workers Joyce Gagnon and Mike Jones provided first hand experience with some of the issues that plague direct care and personal assistance work: low wages, unreliable work hours, and employers who can't provide benefits like sick or vacation time. Their employers and other members of the Coalition present their disparaging news about the impact of Medicaid cuts, no cost-of-living adjustments over years to cover the rising costs of operations and the worry of having to compete with call centers offering higher wages and benefits. While the administration responded sympathetically, they did not give any reason for optimism. Since this presentation, direct care workers and agencies have reported a worsening picture with reductions in hours and the growing challenges of providing fewer hours of service to clients whose service hours have been cut. This sets the tone for the Coalition as it prepares its report to the Legislature's Health and Human Services Committee in March.

CD-PAS Work Group Update

by Joyce Gagnon

The Maine Legislature asked the Commissioners of Labor and Human Services to recommend strategies for improving services for the Consumer-Directed Personal Assisted Service (CD-PAS) programs. The working group submitted their recommendations in December 2004.

35 private consumers and individuals from agencies contributed to the report over 4 months. The goal was a shared desire to maximize consumer choice, promote independent living, encourage personal and family responsibility, and offer benefits to a broader population of existing consumers. Achieving these goals will hopefully allow consumers to make more informed choices throughout the intake and follow-up processes.

The working group acknowledges the need for expanding consumer direction to include the use of surrogacy and/or alternative decisionmakers. These could include a consumer who has a guardian may participate in consumer-directed programs provided the guardian is willing to meet all requirements for participation in the programs; and/or a consumer with cognitive capacity as currently defined by rules may participate in the consumer-directed programs by creating a legal relationship, such as a power of attorney, who is willing to meet all the requirements for participation in the program.

Also recommended was the need to address job classification, livable wages and benefits across all programs in order to attract and retain personnel.

With continued support of Maine PASA and other agencies, problems can be addressed and improve the system and enhanced the quality of life for the individuals we are trying to help.

Maine Updates (cont'd)

Career Centers in Portland and Lewiston work with

DSP employers to support recruiting

A collaboration between the Department of Labor and provider agencies in Maine is forging a cooperative process to inform people of careers in direct support. The process is expected to help people utilizing the Career Center to hear about and apply for direct support jobs with area agencies in southern and western Maine.

Northern New England LEADS Institute Opens in Maine

LEADS stands for Leadership, Education and Advocacy for Direct Care and Support Staff. The Paraprofessional Healthcare Institute (PHI) has invited Maine, Vermont and New Hampshire to develop the LEADS programs over the next three years. Home care and long-term care organizations will be selected to participate in training, leadership and public education activities that will demonstrate best practices in employment and person-centered services for consumers/residents. For additional information, please contact Elise Seala at USM's Muskie School (228-8423) or Christa Baade at CEI (882-7552). This initiative is funded by grants from the Jane's Trust and Langeloth Foundations.



You spoke and we listened!

Personal Assistants, Caregivers, and Employers:

Maine PASA Connections is an online listing and information service that connects people who need assistance in their homes with people looking for employment.

Maine PASA invites people who work in personal care and support (PSS, PCA, CNA, HHA, and others) to fill out an online application.

There is no cost to be listed.

Employers can register online to search our database of available workers.

Finally... the right Connection!

Visit our website www.maine-pasa.org and click on "Maine PASA Connections".

National Updates

The National Directcare Clearinghouse has posted articles on working conditions in consumer directed care and more on their website. Check out their Portrait Gallery! <http://www.directcareclearinghouse.org/news.jsp>

The Direct Care Alliance will hold its annual conference December 3-5, 2005, in Orlando Florida. The conference will be co-sponsored by the Pioneer Network, a leader in long-term care initiatives. The theme of the conference will be to celebrate, reward and recognize direct care workers. Fund raising contributions will be needed to support the travel and registration costs for Maine PASA members to attend. Over the next year the DCA will be reviewing strategic efforts to reach out and to support the state-based associations. Please check their website for updates: <http://www.directcarealliance.org>

DSP Featured in Wall Street Journal Article

In a *Group Home, Caring for Disabled Takes Toll on Ma* was a feature article in the December 15, 2004, edition, page 1A. The article presented the real life and compelling story of Sarah Ahmed. Her story presented the commitment and compassion of the Direct Support Professional and has helped to raise public awareness and appreciation for the demands of the job. To read the article go to: <http://www.namimass.org/news/news04/ad122704.htm> (Point of interest: Ms. Ahmed is described as making \$12.06/hour working in Maryland. This is significantly higher than the average DSP wage in Maine \$9-11/hour.)

ANCOR Site Presents National Picture

For the latest information on the federal budget, Medicaid and efforts to increase awareness and support of DSPs check this website: http://www.ancor.org/2004/issues/budget/index_president_budget.html

Medicaid CMS Administrator Addresses Medicaid Reform

Mark McClellan, chief administrator for the federal Centers for Medicare and Medicaid spoke about the future of Medicaid during a speech at the 2005 National Health Policy Conference. He said the program is "not just about flexibility, it's about flexibility that works," also saying that the current waiver system is too cumbersome for states to make innovations in their program offerings. According to the journal *Healthbeat*, his comments appeared to indicate that "Medicaid reimbursement... would be tied in some way to meeting standards for saving money, improving treatment or expanding coverage." *Healthbeat* reports that "[s]igns point" to the replacement of waivers with performance measures "as the procedural hurdle state Medicaid programs would have to clear to adopt programs to save money or widen coverage." McClellan also spoke in favor of making home- and community-based care "an integral part of Medicaid" and promoted disease management and prevention programs. He also advocated allowing parents to use Medicaid funds to pay for children's coverage if they can't afford family coverage through an employer. (See the ANCOR website, above, for the full article.)

Fund\$ Available to Maine PASA Members for Best Friends™ Training

Maine PASA has received funds to pay members to attend the Best Friends™ Approach to Alzheimer's Care training program. Stipends of \$50.00 per day are available to Maine PASA members who complete the one- or two-day program hours and who are not being paid by their employers to attend. The cost of registration is also covered.

Registration is required, as the number of seats and stipends is limited. Receipts of attendance are to be submitted to Maine PASA for payment.

This training addresses a number of the sources of caregiver strain and dissatisfaction including an emphasis on the importance of the relationship between the caregiver and the person with Alzheimer's and improved skills for handling difficulty behaviors. The Alzheimer's Association has organized programs throughout the state.

Advanced registration is as easy as 1-2-3:

1. Check Call Jan Halloran for a program schedule and to register (287-0233 or e-mail jan.halloran@maine.gov)
2. OR you can also see the program schedule on the Maine PASA's Events page: www.MainePASA.org/events.htm and call the trainer listed.
3. Call Maine PASA 1-800-268-6612 to request the stipend funds.

Tell your employer about this great opportunity and get the help you need to attend!

The funding to support this program is being provided through the Maine Alzheimer's Project and a grant from the Administration on Aging, Alzheimer's Demonstration Grant. To learn more about Best Friends™, check out "Someone to Care for the Caregiver: Karen Bragg's Story" in this newsletter!

Books To Share

Guide Helps Assisted Living Caregivers Facilitate Resident Independence

Encouraging Independence, Choice Control and Decision-Making: Ideas for Direct Care Staff. This guide, which helps assisted living caregivers best facilitate residents' independence, is part of a series of 4 created for assisted living consumers and providers by the Long-Term Care Community Coalition of New York and the Coalition of Institutionalized Aged and Disabled.

For copies, go to <http://www.assisted-living41.org>.



Caregiver Companion Program

by *Romaine Turyn*

The Caregiver Companion Program is a model program funded by the Maine Alzheimer's Project with funding from the Administration on Aging, Alzheimer's Demonstration Grant to States Program. This unique program, we have been told, is the only one that exists in the country. It is a program designed to provide companionship, support, information and education to caregivers of persons with dementia receiving home care provided by the state's home and community based home care system.

To be eligible for home care services, an individual must be assessed by a nurse and require a certain amount of care in order to demonstrate a need for home care. As part of the assessment, the home environment is reviewed, including the availability of informal care provided by family. Statistics show that family and friends are the primary source, or "backbone," of long-term care provided to people who need assistance to stay at home.

In Maine, the coordination of home care services is done by Elder Independence of Maine, which was instrumental in developing the Caregiver Companion Program. The purpose of the Caregiver Companion program is to support the home care program by providing services to the caregiver of persons with dementia. Often the caregiver is instrumental to the success of keeping someone at home. While the home care program provides services to the person in need, the Caregiver Companions provide individualized support and education to the caregiver through a combination of in-home visits, telephone calls, visits in the community, participating in activities such as gardening, or other activity tailored to meet the needs of the caregiver. The goal is to reduce caregiver stress, burden and identify depression for appropriate referrals source.

Karen Bragg has been a Caregiver Companion with Elder Independence of Maine since the Program started. Make sure to read her story, "Someone to Care for the Caregiver," in this newsletter.



It's Tax Time! Did You Know...

The Earned Income Tax Credit is for people who work, but don't earn high incomes. If you qualify, it can reduce the tax you owe, or you may even get a refund. To qualify, taxpayers must meet certain requirements and file a tax return, even if they did not earn enough money to be obligated to file a tax return. Your eligibility is dependent on several factors such as your filing status, income level, and the number of qualifying children you have, if any. There's a lot to know about qualifying, but the most important thing to know is that you can get help figuring it all out. Go to: <http://www.irs.gov/individuals/index.html> or check with your tax preparer.

Movie Review: "Assisted Living"

Fiction Film Dramatizes the Importance of Relationships in Long-Term Care

Assisted Living isn't playing at neighborhood theaters near you, but you might want to catch this story about life in a long-term care facility if you get a chance.

Assisted Living tells the story of a relationship between Todd, a slacker custodian in a multi-level facility, and Mrs. Pearlman, a resident who starts out in an assisted living apartment and is moved to a shared room in a special care unit when her dementia progresses. Though it was filmed in five long-term care facilities and real residents appear in many of the smaller parts, it's not a documentary.

The fictional facility appears to be a good one, run by goodhearted and competent people. Animals and the head nurse's young daughter have free run of the hallways. But the routines and rules, the restrictive "choices" (Mrs. Pearlman is repeatedly asked when

she lingers too long at the nursing station: "Do you want to go to your room or do you want to go to Bingo?"), and the unconsciously paternalistic attitudes of many of the staff contribute to an institutional atmosphere. In the end, despite the staff's best efforts, the residents spend most of the day just marking time. In the movie, as in life, it's the relationships that manage to take root in this thin soil that make the facility feel like a true home - at least part of the time. The slowly unfolding friendship between Todd and Mrs. Pearlman and the impersonal environment they find themselves in leave anyone working in long-term care with a lot to think about.

For more information, including an interview with the director about working with the residents in the film and a list of cities where it's being shown, go to:
<http://www.assistedlivingthemovie.com>.



How to Reach Us

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

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Website: www.mainepasa.org



Maine PASA
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m a i n e PASA NEWS

Volume 4, Number 2

June 2005

Maine PASA Board Seeks Nominations for Board Members

By Jennifer Gillespie, Chairperson – Nominating Committee

You are invited to submit nominations for membership on the Maine PASA Board of Directors. We are seeking direct care and support staff and others who support the mission of Maine PASA.

This is a great opportunity to gain experience in a leadership position. The Board is responsible for organizational planning, fundraising, hiring and managing the executive director, and supporting the mission and bylaws of Maine PASA.

Board members are asked to:

- Attend monthly board meetings,
- Contribute to the discussion and decision making that guides the work of Maine PASA,
- Participate on committees of the board, and
- Represent Maine PASA to its members and the public.

Board members volunteer to serve one or two year terms. Opportunities are also available to serve as an elected officer of the board. The entire Board currently meets once a month, usually on a weekday evening in a location convenient to members. Additional meetings are held for board committee work, workgroups or projects. Regular attendance to meetings (in person or by phone) is expected.

Nominate yourself or another Maine PASA member by completing the enclosed nomination form and returning it by July 15, 2005. Please send nomination forms to: Board of Directors Nomination Committee, Maine PASA, PO Box 710, Norway, ME 04268 or email to: rggedat@exploremaine.com.

Our special thanks to departing board members for their great contributions to the Board and to Maine PASA:

Mike Payne

MFO for Home Care for Maine, who served as our Board Treasurer.

Gail Benvenuto

Project Coordinator, USM Muskie School for Public Service, who served as our Board Secretary.

Ginny Carroll

Employer Assistance Division Bureau of Employment Services Maine Department of Labor.

PASA Forms Partnership with the Consumers for Affordable Health Care

By Lisa Webber, CAHC

Many direct care and home health care agencies nationwide want to be able to offer their staff insurance but can't afford the premiums, or have policies that are unaffordable for part-time and low-income employees and their families. PASA members were polled in May as part of an initiative to make health care more available for direct care and support workers.

The Consumers for Affordable Health Care (CAHC) is a Maine organization working to do something about this. We are a non-profit organization committed to helping Maine people obtain affordable, quality health care. CAHC is reaching out to all home health care, and adult day service providers in Maine to offer our no-cost information and referral services to administrators and their employees. We have been funded to make this outreach through the Health Care for Health Care Workers initiative sponsored by the Paraprofessional Healthcare Institute, a national organization advocating for quality care and quality jobs. We can help families find quality health care coverage in Maine, review options for affordable insurance, interpret insurance policies, negotiate with insurance companies, and obtain coverage for medically necessary services.

Call our Consumer Assistance HelpLine at 1-800-965-7476 for individual assistance or questions about MaineCare, DigoChoice, and other health care coverage options.

More Parents Can Get MaineCare Coverage

As of May 1, 2005
If you have minor child(ren) eligible for Low-Cost MaineCare (formerly "CubCare"), you may now be able to get MaineCare coverage as well!



As part of the Oregon Health Reform, MaineCare became eligible for parents with minor children at home care from 100% to 200% of the Federal Poverty Guidelines (FPL) from for a household of 2, \$2422 for a household of 3, \$3222 for a household of 4, then an extra income step for 5 if you are three, you should apply).

Remember - Assets are not considered for a minor child's eligibility. And, every state an MDT covered against you.

To apply - Call the Department of Health and Human Services office nearest you, and ask to apply for MaineCare parent coverage.

- Wondering if your family meets the guidelines?
- Don't know who to call to apply?
Call us at 1-800-965-7476.

:HELP WANTED:

PASA members are sought who are willing to serve on committees and task forces on behalf of direct care and support workers. Stipends and travel reimbursements are available. Call Roy Gedat at 890-0773.



Board of Directors

- Co-Chair*
Julie Moulton, DSP *Winthrop*
- Co-Chair*
Susan Tucker, PCA/CNA *Biddeford*
- Sherrie Bergman *Brunswick*
- Jennifer Gillespie *Portland*
- Susan Levandoski *Brunswick*
- Roberta Record, PCA *Augusta*
- Elise Seala *Portland*

Executive Director

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Attention PASA Members!!

By Roy Gedat, Executive Director

Welcome to the June issue of the PASA Newsletter. You'll notice a few editorial changes in this issue and I promise there will be many more to come. Newsletters will be more frequent, a quick read email will soon be offered to members who are connected to the web, and opportunities for direct care and support workers to participate and be heard will be offered frequently. Please call, email or write me with your comments and feedback. This is your publication!

Chapter Development – We're going to start local Chapters all over the state. A Bath-Brunswick group will hold an organizational meeting on June 24th, 6:30pm at Bookland Cook's Corner. Bangor/Brewer and Augusta Area members are about to form and we're looking at other areas to begin start-up groups. Meetings will feature guest speakers, support, opportunities and sharing. Call me if you're interested at 890-0773.

Members speaking out – There are many great opportunities for direct care and support workers to participate on committees, task forces, and in conferences. PASA will offer a stipends and travel reimbursements for members who wish to speak out and be heard. We have already sponsored members who testified before the legislature to advance the issue of better pay and benefits. We need involvement on many fronts and in many ways.



Roy Gedat (left) Maine PASA Executive Director; Joyce Gagnon (center) Maine PASA member; Senator Bruce Bryant (right).

A letter from District 72 Representative

Will Walcott

I represent part of the city of Lewiston in the Maine State House, District 72. I am in my second term in the house, winning re-election in 2004 with about 68% of the vote. I serve on the Health and Human Services Committee as I did the previous term.

I am currently employed by John F. Murphy Homes in Auburn, Maine. I work as a DSP at one of the group homes in Auburn. I have worked with people with mental retardation for about a decade. I have been a DSP and residential manager amongst other jobs for various agencies.

Serving on the Health and Human Services committee has offered me the chance to bring a view that is not common to the committee - the view of someone working on the front lines with people with whom the Department of Health and Human Services also works. I have advocated for higher pay for DSP (unsuccessfully due to financial constraints). I also have worked hard to strengthen Mainecare and also expand healthcare to more people. I have worked to make prior authorization of prescription drugs for people on Mainecare easier for people with whom we work. I continue to work on these and other issue. I enjoy my time I spent in the legislature and think I have an important perspective to bring to the legislature relating to the years I have worked as a DSP.

Rep. Will Walcott
Democrat, District 72, Lewiston

Keeping a Policy Focus on Direct Care Workers

by Lisa Pohlmann, MCEP

The Direct Care Worker Coalition has been working together for almost three years now. We currently have 26 organizational members (representing providers, workers and consumers). This April we made our third presentation to the Health and Human Services Committee of the Maine legislature to update them on workers' wages and on various activities underway across the state on the direct care workforce.

The Coalition is seeking next to meet with officials in the new Department of Health and Human Services to discuss "parity" among direct care workers. We have been advocating that CNAs, PSAs, and Home Health Aides should be afforded the same wage floor that Direct Support Professionals currently have -- around \$8.35/hour. While this is still a very low wage for the valuable work all of these women and men do, it is a step in the direction of increasing wages and benefits.

I am pleased to note that the Maine Women's Fund just awarded a \$5000 grant to help with the work of the Coalition in 2005-06!

We appreciate Mike Jones and Joyce Gagnon's presentation to the legislature on behalf of Maine PASA and for their ongoing participation in coalition meetings. Any Maine PASA member should feel free to communicate directly with the Coalition by contacting Lisa Pohlmann, Maine Center for Economic Policy, 622-7381 or lpohlmann@mcecp.org.

••••• **Board positions are available now!** •••••
••••• Nomination form in this issue. •••••

Our Stories

An Open and Loving Heart: Susan Tucker's Story

A Love for Learning

I started doing this work about three years ago. I had taken care of my grandmother and my mother-in-law, but I wasn't getting paid for it. I was just helping them out as they needed it. I would take them to go to the grocery store, or do the dishes or take them to the doctor's. Then three years ago I answered an ad in the paper and got an interview with the director of the agency I work for now.

It was something I always wanted to do, to go into nursing but I took a detour in my life and actually worked for a health insurance company for seven years. Then I had my son, Keatz, and stayed home for seven years. Then I decided to go back to work and answered that ad. I had been working for the agency as a PCA for two years when I took the CNA class. It was tough because I had to juggle work and family and school at the same time. I wanted to do it, even though I knew it would be hectic. The best part of the class was that it was about teamwork. It was like being on a team. We had study groups. We actually had each others' phone numbers in case we had to get together before class. The book for it was interesting, there was a lot to learn because of the medical terms, but the teacher said, "Don't worry about a lot of that stuff. It is more important to know how to be good with people."

I think the best part of being a CNA is the people. Some residents can be a little crabby, but it's because of the kind of day they had. Sometimes they need a hug, it makes their day. I love going in there and seeing their smiling faces. I just got a hug this morning from one of my clients; she was just glad that I was there. A lot of them feel like they're lonely. At least they have somebody to talk to when I come, so they're glad that I'm there. If you're going to take the time to do this job, you've got to take some responsibility for their feelings.



Susan Tucker sees how essential quality care is from a number of different perspectives.

The People make it Worthwhile

After I got my CNA license I was just working in home care, but then the agency I work for contacted me and a couple of others CNAs that did home care and said, "Would you like to do some hours in the nursing home?" I had done my clinical there so I was comfortable doing that type of work. I liked the idea of getting the experience of not only home visits but of the nursing home, too.

In the nursing home I'm go-go-go. I have to answer the bells quickly. You can't spend a whole lot of time. When someone rings you've just got to do what they need and that's it. I think the residents feel like they're being rushed because they don't want to do certain things in a certain time. When they were in their own home they had a set routine. Now they are in the nursing home and they probably feel like they're being pushed around to get ready for breakfast.

Doing in-home work is more relaxed. I'm not rushed when I'm doing my work. In the home I'm free to move around more. In the nursing home I just go from one room to the next. You don't get a whole lot of time with people; it's five minutes here, two minutes there. You should spend more time with people, but you just can't.

Right now I have a total of six in-home people. It switches, sometimes I have five and sometimes I have six. The ones that I have been going to are easy to deal with. There are some limitations they have, they can't do everything for themselves and I might have to do some things for them, but it's not very stressful. They all have something good to say when I come over.

I like the nursing home, but people are easier to get along with when I do home care. I can go at their pace to do things. I think at home they feel happier because they're not in a facility. As long as they can stay in their home for as long as they can they're better off. I like to be in people's homes, they have more there that makes them happy and comfortable. People in the nursing home, it's their home but I think they wish they were back in their regular house. They miss what they used to have and being able to use their own things and have their own schedule. They have very little other than their clothing and personal belongings with them in the nursing home. That must be difficult.

'In the nursing home I'm go-go-go'

What's Most Important

I have direct support workers that come and help my son Keatz. I had Keatz in 1994 and shortly after his birth my mother and

please turn to PAGE 4

continued from PAGE 3

I noticed that there was something wrong. He wasn't responding very well. I had had a normal pregnancy right up until the end, but I had to have a c-section. When Keatz was born, the nurses had drawn blood and taken all the normal tests. That night someone called upstairs to the nurses' station and said, "Put Mrs. Tucker and the baby on antibiotics. They have Group B Strep Meningitis." That's a fatal illness, especially in children. They caught it in time but he ended up with developmental disabilities because of the damage.

After he was about a year old a local agency started a program for younger children with special needs and other problems and he got to go to that until he could start nursery school. After that, he went into public school and has someone come after school and in the summer to work with him. They are mostly young people, young girls. A lot of them were college age or going to be going to college. Kara, who is taking care of Keatz right now, is an HS, Habilitation Specialist.

We've gone through five or six people, and we finally settled with one agency. He went to overnight camp with them in the summer, and he has Kara that comes into the house and works with him. She comes in about three or four hours a week and takes him out into the community and does what he wants to do. She's fun, she's energetic, Keatz likes her. I had gone to other agencies, and they just weren't consistent. The person would call out again and again and he would be so disappointed about the fact that they didn't show up. So finally I said, "Look, I need somebody who is going to be dependable and work with him. If we get a phone call saying that she's not showing up, there should be somebody else you can put with him." When they'd finally hire somebody, we'd find out that they were leaving in a couple months' time. That's no way to hire somebody. If they needed to go to a job with more money or to do something else because they didn't like it, what about Keatz? He likes the girls and gets attached to them and then they are gone. You know, it should work better than this.



Susan Tucker (left) is a CNA who works in and around Biddeford. Susan sees how essential quality care is from a number of different perspectives. As a PCA she worked in homecare, and after getting her CNA license agreed to split her time between nursing home and homecare work. She is very committed to her job and her consumers and so has learned to adapt to both jobs, though they offer their own unique challenges. She has also managed support workers in her own home who come in to work with her ten year old son, Keatz. Keatz has benefited greatly from the Habilitation Specialists that have worked with him over the years and Susan is clearly a proud, loving mother. She sees the problems and virtues in the direct care and support workforce and continues her investment in it with quiet dignity and a real commitment to make things better for those working around her.

The Maine Disability Advocates Coalition – MEDAC

The Maine Disability Advocates Coalition is a coalition of disability advocacy organizations and individuals who meet every second and fourth Tuesday of each month to discuss the important issues and events of relevance to people with disabilities.

The Maine Parent Federation hosts a conference call for all of these meetings, if you cannot participate in person. The number is 1-888-922-5646. The Access Code is 2145.

The location of these meetings is not permanent. Please sign-up for the MEDAC list serve and/or contact Andrew Roth-Wells at aroth-wells@maineddcc.org or 287-4221 to find out where the next meeting will take place.

Board members speak out:

Julie Moulton, CRMA - Opportunity afforded me in the past year on the board:

- Self advocacy
- Leadership Development
- Brainstorming, and Sharing knowledge and experiences with other states
- Promote the professionalism of the work
- Build connections for support

I was afforded the opportunity to speak up, and speak out, about the challenges of providing support to folks with disabilities and to inform people how critical a well trained, adequately paid workforce is to the delivery of superior services.

Roberta Record, PCA - Through the friendships I have developed with Maine PASA, I was able to find my present job after a caregiver recommended my name to help care for the elder she is caring for. The elder was going to be placed in a nursing home and my friend was going to lose her job. The family called the agency I work for, and asked for me as their caregiver. I am now working 40 hours, which I have never worked in this agency. The family is very happy with my professional skills I bring to this elder's home. The caregiver friendships are a great source of comfort and give insight to my work world that others wouldn't understand.

Great opportunity to support and strengthen direct care workers. Fill out and return the nomination form!!

The Muskie Center Perspective: Connection for the Future

An update from Elise Scala

Maine PASA's transition from a grant project to a non-profit organization felt a bit like a boat launching. The analogy came to mind when our focus was on developing the structure and organizing the crew. I can say with confidence that the organization is now sailing in the capable hands of the members, board of directors and executive director. But wait. I am not standing on the shore waving as it sails off!

Maine PASA's development involved many people and organizations. These relationships continue to serve as important ties and resources for Maine PASA's mission and future. It is time for new analogy...seeds, vines, blooms, chapters???

Here are some of the important connections that I am working on from my position as project director at the Muskie School of Public Service, Health Policy Institute:

- The Direct Service Worker Demonstration Grant is working with Maine PASA to inform and engage direct care and support workers in discussions of health insurance coverage and Dirigo Health. This project will feature the Employer of Choice Program. Employers are participating so workers and other employers can learn about the recruitment and retention initiatives in Maine. The grant includes an evaluation of retention interventions like health insurance and other programs.
- The National Direct Care Alliance is looking to Maine PASA as one of the state-based initiatives for building direct care and support to lead and advocate for quality jobs and quality care.
- Maine's Direct Care Worker Coalition provides a platform to promote worker policy and practices that respect and value direct care and support workers in order to sustain quality direct care services in Maine.
- The Paraprofessional Healthcare Institute (PHI) has selected Maine to implement a portion of the Health Care for Health Care Workers campaign. They are currently working with Maine's Consumers for Affordable Health Care to conduct outreach and provide information about health coverage options to workers and their employers. PHI is providing leadership in the effort to raise awareness and financial support for direct care workforce initiatives.
- The Northern New England LEADS initiative is advancing best practices in long term care Maine PASA as an important component in the system for advancing quality of care for elders by increasing the quality of the work experience for direct care workers.
- The Alzheimer's Association is supporting the training of direct care workers in the Best Friends Approach and offers Maine PASA members financial support to attend.



Elise Scala: the founder and guiding light of Maine PASA.

Elise Scala is the founder and guiding light of PASA who continues to offer her wisdom and expertise to the goal of providing recognition, opportunities and quality jobs for personal assistance workers.

Employer in the Spotlight

Partners in Caregiving, Inc., Biddeford

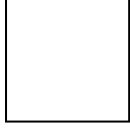
By Elise Scala

John and Joline Pothier, RN, BSN, RFA take great pride in their business of caring for elders and for employees. Partners in Caregiving, Inc. provides geriatric residential care services in Biddeford. In a recent visit to the Shaw House it was clear to see the commitment of their mission to provide a holistic approach and high standard of support and individualized care for elders that emphasizes supporting and enhancing quality of life. The purpose of my visit was to ask John and Joline about their recent decision to enroll in DirigoChoice and to offer their employees an option to purchase health insurance coverage. This is a decision facing many employers and one that is of interest to Maine PASA, its members and the many supporters that identify the need for health care coverage that is affordable and accessible to direct care and support workers with limited incomes. It is a pleasure to feature Partners in Caregiving, Inc. in our first Employer Spotlight and to recognize their commitment to their direct care employees.

How valuable is health insurance as a benefit for recruiting and retaining direct care workers? John and Joline speak from experience when they talk about the high cost of advertising for new staff, training and other turnover costs. While they had to make investments of time and money to learn about the product and inform their employees, they are pleased with the results. In only a few months they have seen how the benefit can make a difference. "It has worked. We have people who have chosen to come to us now with the insurance." The information they got from their insurance producer was necessary and helpful. John and Joline also took the time to learn about the choices and the financial subsidy for low income households that DirigoChoice offers and the value of the investment in their business. Their choice, and the choices of their employees to enroll, demonstrates a commitment to the job. How valuable is this commitment? Some insight is available through testimonials on Partners in Caregiving, Inc website: www.picgi.com.



Maine PASA
P.O. Box 710
Norway, ME 04268



Board of Directors Nomination Committee
Maine PASA
P.O. Box 710
Norway, ME 04268

Fold Here

Fold Here

**Maine PASA Board of Directors
Nomination Form**

Nomination for service on the Maine PASA Board of Directors

Instructions:

1. Please complete all questions below.
2. Nominations forms received by July 15, 2005, will be included in the first review. Nominations will be accepted until the needs of the board are met.
3. Please detach form along dotted line.
4. See back of form for folding instructions.
5. Tape shut.
6. Use proper postage.
7. Mail completed form to:

Board of Directors Nomination Committee
Maine PASA
P.O. Box 710
Norway, ME 04268

Date: _____

I nominate _____ (print name) to the Maine PASA Board of Directors.

Please describe why this person should be considered for membership including any direct care and support work experience and/or insights and special skills you feel they will contribute to Maine PASA, its mission and members.

Please provide nominee contact information:

Nominee Contact Information:

Name: _____

Address: _____

Telephone #: _____

E-mail: _____

Nominated by: _____ (optional)



Maine PASA
 P.O. Box 710
 Norway, ME 04268

Best Friends™ Training

*June 20, 2005 & June 21, 2005
 8:30 a.m. – 3:30 p.m.*

Falmouth
Sedgewood Commons
 22 Northbrook Dr.
 Falmouth, ME 04105
 Trainer: Lesa Andreassen
 Call: Barbara Berube 865-4097

June 29, 2005 8:30 a.m. – 12:30 p.m.

Biddeford
St. Andre Health Care Facility
 407 Pool St.
 Biddeford, ME 04005
 Trainer: Liz Weaver
 Call: Kara Cross 282-5171

Contact Jan Halloran at 287-9233 or at Jan.Halloran@maine.gov for further information regarding above listed trainings, about the additional trainings being scheduled, or about having a training at your organization or program.

Stipends are available for Maine PASA members to participate in a Best Friends™ training. Please contact Roy Gedat at (207)-890-0773 or at rgedat@exploremaine.com for more information.

In This Issue:

- Nominations for PASA Board of Directors - a great opportunity for volunteer service. Leaders sought who want to make a difference.
- Stipends for members. Call Roy to inquire.
- Chapter forming. First meeting of the Bath/Brunswick chapter: June 24, 2005, 6:30 p.m. @ Bookland at Cook's Corner.

.....
 !!! ***The PASA Board needs you !!!***

Coming soon:

- Legislative report.
- email news.
- More opportunities for members.
- Chapters in Augusta and Bangor.

Maine PASA Activity Timeline

The following chronological listing highlights the work and development of Maine PASA between October 2001 and October 2005.

October 1, 2001

Federal Centers for Medicare & Medicaid Services awards Real Choices Systems Change Grant to the State of Maine. Muskie School of Public Service contracted to coordinate projects. Elise Scala appointed to coordinate Workers' Guild project.

Spring 2002

Direct Care Worker Coalition
Augusta, ME

Maine PASA (not named at the time) is introduced at the start of the grant-funded coalition to support direct health care workers and serves its need for worker representation.

October 21, 2002

"Direct Care and Personal Assistants"

Elise Scala, Maine PASA Coordinator, writes article and publishes it in the *Employment Times*.

October 26, 2002

Opening event: "Breakfast for Personal Assistants and Direct Care Workers"

(*Note: This would later be named as the 1st Annual Maine PASA Conference.*)
Lewiston-Auburn College, Lewiston, ME

A group of attendees from the event agrees to join a work group to start the Association and becomes known as the Founding Members.

January 2002

The Founding Member group starts meeting monthly to develop the Association, its name, mission and membership. The group meets for over two years and becomes Maine PASA's first Board of Directors.

November 2002

First edition of Maine PASA newsletter published.

December 12, 2002

Maine Health Care Association
Augusta, ME

Elise Scala, Maine PASA Coordinator, presents the plan for a direct care worker association to the Board of Directors.

February 2003

Maine PASA Founding Members draft the organizational mission statement.

February 4 and April 2, 2003

Direct Care Worker Coalition presents legislation to low address wages and benefits. Members also represent direct care worker interests in public hearing presentation to Maine Legislators in support of LD 1090.

March 2003

Maine PASA Founding Members design logo to fit finalized mission statement.

Maine PASA Activity Timeline

1

April 2003

Maine PASA begins facilitating a monthly telephone conference of other state-based associations to encourage technical assistance and collaboration. This group names themselves the New England Coalition of Worker Associations and Advocacy Projects. *(Note: After two years of meeting, the group expanded to add southern and Midwestern state associations. The Direct Care Alliance, a national advocacy organization formed by the Paraprofessional Healthcare Institute, was asked to take over the role of coordinating the calls.)*

May 2003

Health Care Job Fair
South Portland, ME

Maine PASA staffs a vendor table. The Founding Members rehearse to staff the full day program and conduct outreach to recruit members. Flyers are distributed, the logo is previewed and a number of members are recruited.

June 2003

Maine PASA debuts its new logo and brochure. 7,000 are printed and distributed over the next 2 years.

June 25, 2003

New England Coalition of Worker Associations and Advocacy Projects meets in person.
Portsmouth, NH

Maine PASA receives funding from the Real Choices Technical Assistance grant—through the Rutgers University project and the National Academy for State Health Policy—to hold a regional meeting of the Coalition (New Hampshire, Vermont, Maine, Massachusetts and Connecticut) to discuss worker organizations and advocacy.

July 2003

Maine PASA researches and prepares reference list of worker associations in the US.

Fall 2003

Joint Advisory Committee on Elder Issues
Augusta, ME

Maine PASA invited to provide direct care worker representation and to serve on an ongoing basis.
Founding Member Roberta Record, PCA, attends.

September 2003

Paraprofessional Healthcare Institute recognizes Maine PASA with an article on the Direct Care Clearinghouse website (http://www.directcareclearinghouse.org/worker_assoc.jsp).

October 1, 2003

Maine awarded CMS Direct Services Worker Demonstration Grant. Maine PASA is subcontracted to engage workers and build communications resources and member information.

October 16, 2003

16th Annual Direct Support Professionals Conferences: “Communications and Community Connections”
Bangor, ME
Maine PASA introduces Association through panel presentation and display table. Founding Members Trish Porter, DSP, Julie Moulton, DSP, and Elise Scala, Maine PASA Coordinator, presented a workshop on Maine PASA and the role of a professional association for DSPs.

October 26-28, 2003

National State Units on Aging, National Home and Community-Based Waiver Conference Milwaukee, WI

Maine PASA member, Trish Porter, DSP, presents and serves on panel entitled “Joining Forces: How Associations of Direct Care Workers Create Stability and Quality.”

November 2003

Elder Issues Partnership

Augusta, ME

Maine PASA signs on to be an active member to advocate for elder issues and workforce.

November 14, 2003

2nd Annual Maine PASA Conference: “Building Our Capacity and Valuing Our Work” Lewiston-Auburn College, Lewiston, ME

Winter 2003

“Some Look to Professional Organization to Ease Care Worker Strain”

Alpha One’s Karen Farber writes an article about Maine PASA and publishes it in Alpha One’s publication, *I-it-5*.

December 2003

Maine PASA launches Our Stories, an oral history project to engage and document the work of direct care and support workers by recording their own words and stories.

January 2004

Maine PASA begins work to establish its first Board of Directors. A consultant from the Maine Association of Non-Profits is contracted to facilitate a sub-committee and draft a plan to form the Board and to recruit members.

February 28, 2004

Maine PASA Portland Chapter introductory meeting

March 2-3, 2004

CMS Grantee Conference

Baltimore, MD

Maine PASA Founding Members Julie Moulton, DSP, and Susan Tucker, PCA, present and staff a poster session with Maine PASA display and materials. The pre-conference presentation includes presentations by Julie and Roberta on 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.

March 13, 2004

Augusta Chapter introductory meeting

March 27, 2004

Brewer Chapter introductory meeting

April 2004

Maine PASA joins a workgroup to participate in the ANCOR (American Network of Community Options and Resources) and Maine Department of Labor Grant to address recruitment and retention of Direct Support Professionals through the Portland and Lewiston Career Centers.

- May 4, 2004**
Maine PASA Board of Directors holds its first retreat.
- May 4, 2004**
National Association of State Directors of Developmental Disabilities Services (NASDDDS) Portland, ME
Maine PASA members (Julie Moulton, DSP, and Elise Scala, Maine PASA Coordinator) participate in panel presentation on the role of the direct support professional in managing challenging behavior and ensuring a quality of life for consumers.
- June 3-5, 2004**
14th Annual Rural Geriatric Conference: “Enhancing Mind, Body and Spirit: The Geriatric Health Imperative”
Bar Harbor, ME
Maine PASA Founding Members Roberta Record, PCA, and Elise Scala, Maine PASA Coordinator, introduce Maine PASA and present on the value of direct care workers and the importance of recognition and support.
- June 9, 2004**
Portland Chapter meeting and workshop
- June 19, 2004**
Brewer/Bangor Chapter meeting and workshop
- June 23, 2004**
Augusta Chapter meeting and workshop
- June 25, 2004**
Maine PASA Board of Directors holds its first retreat. A consultant facilitates group development and strategic planning.
- August 2004**
Maine PASA Connection Advisory Board convenes.
- September 2004**
Brewer/Bangor Chapter meets to organize and plan monthly meetings.
- September 2004**
Legislative Task Force: CD-PAS Work Group
Augusta, ME
Maine PASA asked to serve on task force as an organization representing direct care and support workers to make recommendation for changes to the Consumer Directed Personal Assistance Services programs and procedures. Joyce Gagnon, PA, and Elise Scala, Maine PASA Coordinator, attended all meetings. Joyce writes a section in the final report prepared for the Commissioner of the Department of Health and Human Services.
- September 17, 2004**
Maine PASA members visits Maine Congregational Representative Tom Allen’s office in Washington, DC, to introduce themselves, their organization and their purpose. Materials were also provided to Susan Collins’ (US Senator) and Michael Michaud’s (US Congress) staff.

September 18-20, 2004

DCA National Conference (Direct Care Alliance): “Building Unity for a Valued Direct Care Workforce” Washington, DC
Maine PASA presents two workshops, “Options for Worker Participation” and “Telling Our Stories.” A poster session was also conducted on the Our Stories project.

September 27, 2004

3rd Annual Maine PASA Conference: “Excellence in Long-Term Care” Augusta, ME

This conference was co-sponsored with Maine Long-Term Care Ombudsman Program, Maine Healthcare Association, First Atlantic Healthcare and Maine Home Care Alliance. Maine PASA also hosted an annual meeting reception to introduce the Board of Directors to Maine PASA members.

October 27, 2004

Muskie Research and Public Service Fair
Portland, ME

Maine PASA displays the Our Stories Project in a University of Southern Maine Muskie School graduate degree program poster session.

November 2004

Maine PASA is incorporated and registered with the State.

November 2004

St. Andres Rehabilitation Center
Boothbay Harbor, ME

Elise Scala, Maine PASA Coordinator, presents information on the long term care workforce and the grant initiatives to improve recruitment and retention to a Coastal consortium of long-term care facilities staff.

December 2004

Maine PASA conducts competitive search for an Executive Director.

December 2004

Maine PASA conducts phone survey to poll Maine PASA members on their requests for programs and services, their use of Maine PASA newsletter and website, and their interest in local Chapters.

December 2004

Maine PASA Connections goes live.

January 2005

Maine PASA granted 501(c)(3) status.

January 2005

Maine PASA hires Roy Gedat as Maine PASA’s Executive Director.

January 2005

Maine PASA funded by Real Choices Rutgers for regional meeting with Vermont Association of Professional Care Providers. National Academy of State Health Policy helps to facilitate and publishes report of the event.

January 2005

Maine Alzheimer's Project awards contract to Maine PASA to fund member attendance to Best Friends Approach to Alzheimer's Care™ training programs.

February 2005

Conference on Aging
Portland, ME
Elise Scala, Maine PASA Coordinator, presents workshop describing the direct care workforce recruitment and retention initiatives being conducted in Maine.

March 2005

Southern Maine Area Agency on Aging
Scarborough, ME
Maine PASA members present to Area Agency affiliates about Maine PASA, addressing recruitment and retention needs and the relationship between quality care and quality jobs.

May 2, 2005

Community Health Worker Program Conference
Augusta, ME
Roy Gedat, Maine PASA Executive Director, presents a workshop about Maine PASA and its mission.

June 2005

Home Care Alliance of Maine
Maine PASA becomes a member.

June 2005

Developmental Disabilities Council
Maine PASA becomes a member.

July 2005

Nominations for new board members requested marks the completion of one-year board member terms.

September 2005

Maine PASA works with the Maine Long Term Care Ombudsman Program and the Maine Health Care Association to co-sponsor the 2005 "Excellence in Long Term Care" Conferences
4 Locations in Maine: S. Portland, Orono, Caribou, Newcastle
Poster Session presented and Maine PASA shirts and tokens are given to attendees.

September 2005

Maine PASA prepares grant applications in partnership with PHI, Vermont Association of Professional Care Providers to Bingham Betterment Foundation, Jane's Trust, and Maine Initiatives. The proposals include objectives for building Maine PASA's operating capacity and member programs, supporting operations and actively participating in the health care for health care workers initiative. This grant also includes funding for Maine PASA to establish leadership apprenticeship positions for worker members.
(Note: The Jane's Trust grant was awarded in October.)

October 1, 2005

CMS Real Choices grant ends September 30th and operations are fully transferred to Maine PASA for independent operations.