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ISSUE BRIEF



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SYNOPSIS Direct-care workers have a critical role to play in improving the quality of long-term care services. To make the most of their ideas and creativity, their voices must be heard. Fortunately for all long-term care stakeholders, more direct-care workers are raising their voices – both in public policy debates and in workplace change initiatives – about how best to support their efforts to provide quality long-term care services to consumers. This issue brief explains why direct-care worker involvement at all levels is important and illustrates how workers are getting involved through worker associations, unions, and employer-initiated workplace change initiatives. It also suggests guidelines to ensure that worker input is fully utilized and valued.

Direct-Care Workers Speaking Out On Their Own Behalf

INTRODUCTION

In 2001, Mary Winchell, a direct support professional in Ohio, testified to the human services subcommittee of the state's House Finance Committee. Speaking in favor of a bill that would earmark additional funds to compensate direct-service staff, Winchell talked about the satisfaction she got from her work and the frustration of trying to split her time between too many clients at once.

Winchell works at HAVAR, a community-based organization that serves people with mental retardation and developmental disabilities. After 15 years as a direct service professional, she makes \$10 an hour — more than many other direct-care workers but substantially less than people in her town earn for making doughnuts. What she and her peers need most, she told the committee members, was "a higher wage to meet our own personal needs."

HAVAR Executive Director Debbie Schmieding, who helped Winchell prepare her testimony, says: "I think it made a huge difference. [The legislators have] heard enough from people like me — administrators and bureaucrats. I think they were quite responsive." The bill passed, putting more money in the budget for direct service workers' wages during the biennium ending June 30, 2003.

Worker participation has also benefited Ridgeview Health Care Center in Cromwell, Connecticut (part of the Apple Health Care, Inc., chain of nursing homes). There, workers joined staff at all levels of the organization in planning and implementing a Pioneer Networkinspired culture change initiative in the late 1990s. As part of a Better Life Committee, direct-care workers raised concerns about the unwelcoming break room that lacked equipment for preparing snacks and meals. The committee redesigned the unadorned space, transforming it into a popular gathering place with the addition of cabinets, a microwave, a refrigerator, plates, utensils, and warm and inviting decorations. In addition to serving a tangible need, the room conveyed the message that staff were a respected part of the nursing home community.

These are just two examples of how workers' voices can make a difference. In the policy arena, the personal testimony of workers has a profound impact on legislators who often know little about the important, life-sustaining relationships that caregivers have with residents and clients. In the workplace, involving workers in change initiatives ensures that changes



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are meaningful to workers and support them in delivering high-quality care.

This issue brief describes how direct-care workers are speaking on their own behalf to improve workplace practices and public policies that affect their working conditions,

salaries and benefits, and opportunities for professional growth. It discusses:

- Why worker participation and empowerment is important to quality improvement
- How workers can make a difference in campaigns to influence public policy



"Direct care workers want a voice to represent them, a means to secure continuing education, an organization to represent their needs, and a mechanism to network with other professionals."

In Their Own
Words, Part II,
Pennsylvania's
Frontline Workers in
Long-term Care,
Pennsylvania
Intra-governmental
Council on
Long-Term Care,
October 2002

Avenues for Involving Direct-Care Workers

orkers are being drawn in to efforts to improve the quality of care and the quality of direct-care jobs through many types of groups. These include: worker associations; unions; employer-sponsored policy action groups; workplace committees to address care delivery and other workforce practices; and, multi-stakeholder coalitions.

Worker Associations

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.

The Maine Personal Assistance Services Association (Maine PASA) and the Direct Care Workers Association of North Carolina are two new worker associations created with funding from Real Choices Systems Change grants from the U.S. Department of Health and Human Services' Centers for Medicare & Medicaid Services. Susan Harmuth of the North Carolina Office of Long-Term Care says her office founded the North Carolina association in part to provide workers with educational and professional development opportunities. However, she says, another goal is to provide an avenue for workers to take "a seat at the table at public policy discussions and other structured meetings where broad-based coalitions are brought together."

A handful of worker associations are national, such as the National Association of Geriatric Nursing Assistants (NAGNA), but most operate within only one state. Some represent workers in a wide range of long-term care settings, like the Iowa CareGivers Association, whose approximately 1,500 direct-care worker members work in nursing homes, hospitals, residential care facilities, assisted living facilities, hospice and home care. However, many represent just one kind of worker. All worker members of the Connecticut Association of Personal Assistants, for instance, are personal assistants who provide home-based services for people with disabilities.

Unions

Since they first targeted the long-term care sector in the early 1990s, labor unions have made rapid strides in organizing direct-care workers. Unions provide workers with a vehicle for improving their working conditions, not only by changing workplace policies and practices through collective bargaining but by influencing public policy. Several locals run training programs to teach workers how to become leaders, which generally include educational sessions on how to lobby government officials and how to talk to the media about the challenges workers face. Workers representing the Service Employees International Union (SEIU), for instance, have occasionally testified at US Senate hearings, and they frequently visit state legislators to advocate for pending bills.

Nationwide, almost 350,000 CNAs, personal care attendants, and home care aides are members of the SEIU,9 while another 60,000 are part of the American Federation of State, County and Municipal Employees (AFSCME).10 A few thousand others belong to other unions, primarily the American Federation of Teachers and the United Food and Commercial Workers. Together, they represent roughly 15 percent of such workers across the country,11 but union penetration varies widely from state to state, with tens of thousands of direct-care workers unionized in California and New York, more than 25,000 in Illinois, and none in Mississippi or the Dakotas.12

Unions primarily negotiate with employers to win improvements in wages, benefits, and working conditions, typically within a highly structured legal frame-

- Organizations and advocacy groups that prepare direct-care workers for leadership and advocacy roles and involve them in change efforts
- How to avoid common roadblocks to effective worker participation

work. Therefore, depending on the particular relationship between labor and management, a union presence can either facilitate or complicate organizational change efforts (for details, see Avoiding Common Roadblocks below). In addition, unions often want to join forces with others, particularly to advocate for legislative changes. "There's incredible power in working together," says Katherine Cox, health policy analyst for AFSCME. "When you go to [Senator] Grassley's office and there are people from the nursing home industry and the union sitting down together and you say, 'we all want X,' they listen to that."

Stakeholder Coalitions¹³

Some workers are joining coalitions with other long-term care stakeholders to influence policy and practice. The Direct Care Alliance (DCA), a national coalition of consumers, providers and workers, is dedicated to improving the quality of care for consumers by improving the quality of jobs for direct-care workers. The DCA strives to incorporate direct-care workers' perspectives and voices in all aspects of its work, including workers on its board of directors and encouraging and supporting their participation in national conferences and legislative hearings.¹⁴

The five BJBC state coalitions include workers at all levels of project planning and implementation, both in the workplace and policy arenas. Three states -Vermont, North Carolina, and Iowa — have statewide worker associations that are playing a formal role in their coalitions, most notably in Iowa, whose coalition is led by the Iowa CareGivers Association. In Oregon, SEIU is a member of the coalition and the state's unionized public authority will be one of the leadership sites for the BJBC workforce demonstrations, and Pennsylvania's coalition includes a representative of SEIU Local 1199P and several workers who have worked together on similar issues for years as part of the Workforce Issues Workgroup, a multi-stakeholder group brought together by the state Intra-Governmental Council on Long-Term Care.

EMPOWERING DIRECT-CARE WORKERS IS IMPORTANT TO QUALITY IMPROVEMENT

Direct-care work is poorly paid and undervalued, partly because the workers are mostly women and minorities and partly because the jobs are seen as requiring minimal education and training. This attitude, however, is beginning to change. As more long-term care employers learn what it takes to fill vacancies and slow down the revolving door of turnover, they are coming to appreciate the skill required to do the job well.

This change in attitude was reinforced by a 2001 Institute of Medicine report which recognized that the "quality of [long-term] care depends largely on the performance of the caregiving workforce." While adequate numbers of staff are important contributors to quality of care, the IOM report noted, the education, training and competence of workers matters as well, especially in view of increased acuity of nursing home residents and home health recipients.

But even a more educated and skilled workforce can do only so much to respond to residents' individual needs if workplace design and management styles do not support their efforts. Thus, the movement to make nursing homes and other long-term care organizations more resident-centered or consumer-directed identifies as one of its core principles the empowerment of direct-care workers.

The Pioneer Network, for example, recommends that the process of changing the culture of nursing homes be "highly inclusive," involving workers as well as residents and their families, says President Sue Misiorski. Culture change requires strong leadership, she adds, but "the leadership has to be willing to create a decentralized organizational structure that returns as much decision-making power as possible back to the residents/consumers and those who work closest with them."

Empowerment means being able to exercise some independent judgment in the job and influence organizational processes, both of which inspire workers to make a greater investment in the organization. The call for greater empowerment of nursing staff was supported by another Institute of Medicine report, issued in November 2003, which recommended changes in the management, work design, and organizational culture in order to reduce threats to patient safety. That report recom-



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he home health aides in the political action group (PAG) at Cooperative Home Care Associates, a South Bronx-based home care agency, "love what they do and want to continue to take care of people," says Denise Clark, a former CHCA home health aide who now coordinates the group. "And in order for them to do that," she adds, "changes have to be made." About two dozen workers attend the PAG's monthly meetings, where they discuss the difficulties they face as low-wage workers and learn how to advocate for their interests with policymakers, the media, and other stakeholders.

Engaging direct-care workers in public policy campaigns involves not only building enthusiasm for the effort but also making sure the participants have all the information and support needed to function effectively. A consultant with extensive political experience who helps Clark manage and moderate the PAG has provided guidance in how to work for policy change, and the group has educated itself by reading and inviting guest speakers to explain such things as the differences between Medicare and Medicaid. In addition, workshops and one-on-one coaching have covered how to communicate effectively with public officials.

PAG members have engaged in a number of policy-related activities, including registering colleagues to vote and visiting Albany to talk with state legislators. For a recent "Walk in My Shoes" day, the PAG wrote to their representatives, inviting them to visit CHCA aides on the job. The successful day resulted in PAG members forging a good relationship with an aide to a key state legislator, a significant milestone in the group's efforts to make their voices heard.

mended that health care organizations solicit input from nursing staff at all levels on how to reduce clinical errors, identify causes of and solutions to staff turnover, and determine

appropriate staffing levels.²

An increasing body of evidence supports the notion that empowered certified nursing assistants (CNAs) and home care aides can contribute to better organizational performance. In a multi-state sample of nursing homes Teta Barry, a researcher at Penn State University who is on the Better Jobs Better Care (BJBC) evaluation team, found that facilities where the charge nurse delegated more responsibility to nursing assistants had lower nursing assistant turnover rates. Susan Eaton, who before her recent death was an Assistant Professor at Harvard University and a BJBC research grant recipient, found that organizations that emphasize working in teams, improved information sharing between nurses and direct-care staff, and gave greater responsibility to direct-care workers were more likely to show improvement in resident functioning and social activities.3

The Wellspring model of nursing home culture change, implemented by an alliance of 11 nursing homes in eastern Wisconsin over the last decade, and adopted by four other

alliances in the region, also emphasizes CNA empowerment in its efforts to improve clinical care quality and organizational effectiveness. Many components of the Wellspring model contribute to better facility surveys and lower staff turnover compared to other facilities, but the inclusion of CNAs in self-directing care resource teams is a critical one.4 Each team is taught best practices in certain aspects of clinical care, which its members then disseminate throughout the facility. According to a study of the Wellspring model, "the increased voice and authority of the CNAs on the care teams, including their participation in decisions that affect the entire facility, both reflect and create changes in the culture of the nursing homes. This involvement in turn leads to greater understanding, greater commitment, increased excitement, and job satisfaction among frontline staff as well as management staff. This clinical/work culture interface increases the likelihood of follow-through, and, ultimately, increased quality of care."5

Similarly, Dale Yeatts and his team at the University of North Texas documented a correlation between CNA/nurse relationships and patient functioning, finding that homes where nurses share authority and decision-making with nursing assistants tend to be higher performing. Self-managed work teams, with their



The National Association for of Color was organized in 2002 by a group of direct care workers to help nursing assistants, home health aides, personal assistants and other people of color in long-term care overcome the they face on the job due to subtle or overt racism. focus on employee empowerment, are thus an important step towards improved nursing home resident care and reduced staff turnover.

Home care agencies that involve workers in decision making also find that they can improve care and reduce turnover. Quality Care Partners, a home care agency in New Hampshire, found that its scheduling system was causing enormous problems for clients and creating tension between workers. While the system, which allowed workers to choose their preferred hours each month, sounded as if it maximized individual choice, it demanded hours of the scheduler's time every month and made it difficult to arrange for needed coverage on weekends, according to QCP President Rebecca Hutchinson.

After the problems were raised by a worker at a bimonthly staff meeting, the staff agreed to

beyond their employer's control. When educated about the ways that public policies may undermine quality jobs and quality care, some workers feel compelled to speak out. Their participation benefits all long-term stakeholders, as workers bring a unique perspective to policy debates.

When talking with lawmakers, workers provide a valuable reality check by sharing examples of the problems that current policies create in their everyday jobs and lives and suggesting ways to resolve them. In addition, workers bring the passion of their life and work experience to the table, helping decision-makers far removed from the everyday realities of long-term care understand why better jobs make a difference to the quality of care provided to consumers.

Recent testimony from a member of Maine



In the policy arena, the personal testimony of workers has a profound impact on legislators who often know little about the important, life-sustaining relationships that caregivers have with residents and clients. In the workplace, involving workers in change initiatives ensures that changes are meaningful to workers and support them in delivering high-quality care.

set up a task force consisting of LNAs7 and home companions to address them. Members of the task force reported on their progress at staff meetings and solicited input from all interested staff. They also helped Hutchinson explain the new system—which required workers to work more consistent schedules and agree to one or two on-call weekends per year—in one-on-one sessions with the other workers. Not everything about the new system was popular, but knowing that the solutions came from their peers made the workers more willing to accept them as necessary and fair, Hutchinson says. There was little resistance, and according to Hutchinson, the new system is working well.

CHANGING PUBLIC POLICY

Workers empowered to participate in organizational decision-making develop an awareness that their salaries, benefits, and working conditions are often limited by factors that are PASA, for instance, helped convince that state's legislature to consider a bill that would establish a minimum wage for direct-care health care worker wages (CNAs and home health aides) statewide. "The bill had an estimated price tag of \$11.5 million, which we thought might immediately sink it," says Elise Scala of the Institute of Health Policy at the University of Southern Maine's Muskie School, who coordinated the establishment of Maine PASA. The testimony of one member of the group was particularly potent, Scala believes. The worker testified that she made a living wage, but only after having been a direct-care worker for 20 years and having taken on the additional responsibility of hiring and supervising other workers. She then talked about how hard it was to find and keep good staff when the starting pay was barely \$8 an hour. When legislators questioned whether her credentials and education warranted a higher wage, "she told them: 'I have a PhD, which stands for Preserving

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Human Dignity," says Scala. "The response from the legislators was excellent. They were clearly paying attention."

Direct-care workers are also getting involved in public policy in ways that may be less glamorous than legislative hearings, but are just as

important. In New Hampshire, for instance, the Board of Nursing now includes several nursing assistants, who help set policy affecting LNAs. And in Oregon, workers are on several subcommittees of a recently created Homecare Commission, which will determine such things



"The union is starting to make home care a visible profession and the workers feel more pride in their work. Increased wages and benefits and decreased turnover lead to stability of these workers and to better care for

representative quoted in: Collaborating to Supportive Services: Perspectives on California's Public by Janet Heinritz-Canterbury, Paraprofessional Healthcare Institute,

Avoiding Common Roadblocks

t is not always easy to involve workers in public advocacy or workplace change initiatives. Workers may need to learn new skills in order to participate effectively, and those who have traditionally held decision-making power need to be willing to listen and learn and let go of their role as the "expert" or "authority." Below are some common roadblocks to effective worker participation and strategies to address them.

Being outside one's comfort zone. Policymakers and administrators who are accustomed to making decisions affecting workers without consulting them may resist their involvement. At the same time, workers may feel self-conscious, afraid that they'll say the "wrong" thing, sound ignorant, or offend or anger a supervisor. Communication may also break down if the workers are from different socioeconomic, racial or ethnic backgrounds than other members of a group. To overcome these problems, a facilitator or group members may need to make special efforts to draw workers out to ensure that their views are heard. Between meetings, workers may need coaching in how to express themselves effectively while other members of the group may need coaching in how to listen to workers.

A failure to articulate the relevance of the work to daily life. Workers don't always see the group's work as being relevant to them. Most direct-care workers are already juggling a number of obligations, often caring for family members at home or holding down more than one job to pay the bills. Some workers have also been turned off by bad experiences with groups that were ineffective or didn't make good use of their time and energy. People soliciting worker participation need to explain in a clear, concise, and compelling way how the changes they seek would benefit workers and the importance of worker participation in achieving success. This is particularly important in public policy work, since it is farther removed from the day-to-day reality of the workplace. It's also helpful to periodically restate goals and celebrate incremental victories along the way to maintain the group's sense of momentum and purpose.

Time constraints. Because workers generally have so many demands on their time, they may find it difficult to attend meetings. What's more, finding a time when multiple workers can attend can be difficult, since longterm care is rarely a 9-to-5 job. Scheduling breakfast or dinner meetings can make it easier for workers to justify the time spent in meetings. Paying workers for the time they spend in meetings can also help make it possible for them to attend. If a group includes several workers who have different shifts, alternating meeting times could make it possible for everyone to attend at least some of the meetings.

Poor relations or lack of communication between management and workers. Direct-care workers are likely to view even a sincere invitation to participate in workplace change activities with distrust if relations between workers and management have been strained, or if the workplace is very hierarchical with little communication between the two groups. Overcoming distrust requires a sincere interest on management's part in involving workers in the decision-making process. The Pioneer Network suggests that "flattening the hierarchy" is the best way to ensure involvement from all members of the community.15

Reluctance to "air dirty laundry." Managers may be afraid that input from workers will be overwhelmingly negative. In a group trying to change workforce practices, this could lead to conflict rather than consensus. In groups trying to change public policy, airing workers' perceptions of problems in particular organizations may make management nervous, especially if the group includes union representatives. Similarly, workers may be reluctant to talk honestly about problems at their workplace for fear that they'll make their employers look bad or sound like troublemakers. Establishing ground rules about what is said in group meetings agreeig, for instance, that there will be no repercussions for "negative" statements — can minimize these fears. However, how freely people feel to speak ultimately

as the minimum qualifications and training needed to become a homecare worker in the state. According to Karla Spence of SEIU Local 503, workers' input has been instrumental in shaping the committees' recommendations. A worker on the Administrative Rule Committee,

depends on the level of trust among group members.

Starting with an uneven playing field. Every group needs to construct a common language and knowledge base about the subject it is addressing. If some people use jargon that others don't understand or refer to events that others know nothing about, the "outsiders" will have to struggle to keep up, won't be able to contribute much, and may tune out altogether over time. To start everyone on an equal footing, a group can devote an early meeting to ensuring everyone understands the issues that will be addressed and has a chance to ask questions. Group members should also be encouraged to ask for clarification whenever they don't understand something.

A conflict of interest between unions and management. When employers in a unionized organization want to change workforce practices, a mutual lack of trust can make it difficult to enlist worker participants. Union leaders get particularly suspicious when management selects the workers on a committee, "because they often pick the workers who say what they want them to say," according to AFSCME's Cox. On the other hand, management often become wary for the same reasons when unions appoint workers to workplace committees.

Even when relations between management and unions are cordial, union rules may place restrictions on what a workplace practices committee can do. For anything covered in the contract negotiated with the union — which includes wages, hours, and terms and conditions of employment — committees cannot make changes without a waiver from the union. Even things that are not covered in a contract, such as how scheduling is done, may need to be vetted by the union if they could affect things that are covered. That is why it is so important, if at all possible, to ensure that the union is a key partner in the organizational change process along with management. The best way to build that partnership is to ask management and labor to appoint any workplace participation committees jointly.

for instance, which was developing a process for terminating a home care worker's employment, "had a great impact in the development of the rules, advocating for consistency and the ability for the worker to have a fair hearing."

Workers can also help build public support for broad campaigns that shape public opinion and policy by raising awareness of their struggle to provide high-quality service for their clients without sacrificing their own and their families' quality of life. At a kickoff Town Hall meeting in Boston for Cover the Uninsured Week in 2003, a worker and her employer spoke about how lack of access to health insurance and soaring costs affect them. The two represented a workplace participating with the Direct Care Workers Initiative, a multi-stakeholder coalition in Massachusetts, in a project to expand access to health insurance coverage for direct-care workers. The worker testified about hardships she faced as a result of living without adequate insurance while her employer talked about the difficulty of finding an affordable policy. Their shared presentation was the featured event of the meeting and was covered on the evening news.



CONCLUSION

Involving workers in efforts to improve the quality of direct-care jobs and the quality of care for elders and people living with disabilities is critical to success. Employers and policy-makers need to hear from workers and understand their perspective on issues such as vacancies, turnover, training, wages and benefits, and care delivery.

In the workplace, direct-care workers are often closer to the residents/clients than any other staff members. They understand how policies facilitate or interfere with their ability to establish caring relationships and can help ensure that new policies and systems intended to improve quality mesh with how care is actually delivered. Involving direct-care workers from the beginning in evaluating current practices and developing new ones assures that workers will be able to adapt and integrate the new practices into daily routines.

In the policy arena, workers bring their passion for helping others to abstract discussions about issues such as staffing ratios, Medicaid policies, and health care access. No long-term care lobbyist can convey the impact of public policy on the lives of caregivers and those they

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care for in the way that a direct-care worker can. Direct-care worker associations, multi-stakeholder coalitions, unions and other organizations that are empowering workers to tell their stories are helping to reshape the long-term care debate in state houses and on Capitol Hill.

As a result of these efforts, there is growing awareness of the need to strengthen the directcare workforce in order to provide consumers with quality long-term care services today and meet the increasing demand for these services in the future.

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- ⁷ LNA (licensed nursing assistant) is the term used for CNAs and home health aides in New Hampshire.
- Contact information for all national and regional worker associations and links to their websites can be found on www.directcareclearing house.org/worker_assoc.jsp. Descriptions of selected groups may be found in Direct Care Worker Associations and Public Authorities, published by the National Academy for State Health Policy, at www.nashp.org/Files/Direct Care Worker Issue Brief FINAL.pdf Also see "Organizing Direct Care Workers: Benefits and Challenges," Workforce Tools #3, published by the Paraprofessional Healthcare Institute for the Centers for Medicare and Medicaid (forthcoming).
- Personal communication with Catherine Sullivan, SEIU Policy Analyst,
- ¹⁰ Personal communication with Katherine Cox, AFSCME Health Policy Analyst, August 2003
- 11 This represents 410,000 of the 2,400,000 estimated number of home health aides, nursing aides, orderlies, attendants, and personal and home care aides employed in the U.S. in 2000, according to the US Bureau of Labor Statistics. Found online at www.bls.gov/emp/ emptab21.htm
- ¹² Personal communication with Catherine Sullivan
- ¹³ For more on coalitions, see "Multi-stakeholder Coalitions: Promoting Improvements in the Long-term Care Workforce," Better Jobs Better Care Issue Brief, vol.1, no.1, October 2003, at www.bjbc.org/ content/docs/BJBClssueBriefv1n1.pdf
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