

DIRECT CARE WORKERS
AND THE FUTURE
OF LONG TERM CARE:

**A Series of Forums
on the Emerging Crisis
in Caregiving, and
What's At Stake
for All of Us**

FINAL REPORT

JUNE 2004

Iowa Caregivers Association
in collaboration with
AARP Iowa
and the Iowa Office
of the Long Term Care Ombudsman

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EXECUTIVE SUMMARY

Direct care worker issues have significant implications for the current dialogue on reform of long term care in Iowa. For example, consumers are expressing strong preferences for services in their own home, and, increasingly, for consumer-directed care. Questions have yet to be answered as to how to ensure access to adequate in-home supports, in a service delivery system that is fair and equitable both for consumers who choose this option, and for the employees they hire.

In June, 2004, the Iowa Caregivers Association (ICA) conducted four public forums throughout the State on issues related to the increasing demand for direct care workers, on problems in recruitment and retention, and on the implications of these issues for the on-going debate over the future of long term care in Iowa. The principal purpose of the forums was two-fold: to educate consumers and the general public, providers, and direct care workers; and to solicit input from various stakeholder groups on their views of how the issues affected them, and the values they considered most important in design of the State's caregiving system. A secondary purpose was to encourage participants to think about steps they might take themselves, to become part of "the solution."

Direct care workers are the front line caregivers in nursing homes, assisted living facilities, adult day services, home health agencies, residential care facilities, and other places where people receive long term care. Making up 20% of the health care workforce, they serve the elderly and adults and children with disabilities as home care and home health aides, certified nursing assistants (CNAs), respite care and hospice workers, personal attendants, and other classifications. Iowa, like the rest of the nation, faces a growing shortage of direct care workers that threatens to reach critical levels, as Baby Boomers age and as the population of people with significant disabilities continues its sharp increase. The shortage is also due to problems in recruitment and retention, related to such factors as low wages, lack of benefits, inadequate training and career advancement opportunities, and lack of recognition.

Approximately 150 people participated in the four forums in Cedar Rapids (6/8), Des Moines (6/15), Davenport (6/19) and Emmetsburg (6/22). The audience consisted of direct care workers, provider/employers, seniors and people with disabilities, their families, advocates, Iowa legislators, state agencies and interested citizens.

Forum participants spoke out energetically on how the issues affected them, and on the values they thought should be brought to bear in designing a fair and equitable, cost-effective, consumer-responsive system. Consumers, their families, and advocates were almost unanimous in identifying the need to protect individual dignity and respect for the care recipient and the Direct Care Worker as their top priority, through support for a relationship recognizing the needs and desires of both. Direct care workers and their employers also recognized the importance of these fundamental values, but generally assigned at least equal weight to factors related to the quality of care, and a safe working environment for both the consumer and the worker, such as training, manageable workloads and essential worker protections.

The forums were funded by a grant from the Iowa Department of Elder Affairs. ICA also received significant financial and technical support from AARP Iowa and the Iowa Office of the Long Term Care Ombudsman, and assistance in publicizing the events from the Governor's Council on Developmental Disabilities, the Iowa Health Care Association, and the Iowa Association of Homes and Services for the Aging. Community co-sponsors assisted with local logistics and publicity.

I. INTRODUCTION

Iowa Caregivers Association (ICA) was established in 1992 to improve access to quality care by increasing the number of direct care workers and supporting their personal and professional growth. Since its inception ICA has collaborated with workers, service providers and others with a stake in caregiving, to address major issues in the recruitment and retention of a qualified workforce. In recent years, as the State of Iowa began research and an extensive public dialogue on long term care reform, ICA has sought to draw attention to the significance of workforce issues for that reform effort. A series of public forums was planned to educate stakeholders and the general public, and to solicit their ideas about the values that should be at the foundation of Iowa's system of caregiving.

The forums were principally funded through ICA's Direct Care Worker Recruitment and Retention contract, supported by a grant from the Iowa Department of Elder Affairs. ICA also received significant financial and technical support from AARP Iowa and the Iowa Office of the Long Term Care Ombudsman. AARP Iowa assisted with research, forum planning, community publicity, and on-site presentations. The Office of the Long Term Care Ombudsman assisted with research and planning, and supported outreach to direct care workers by funding a small stipend program for up to forty individuals registering for the forums and on-site presentations. Assistance in publicizing the events statewide was provided by the Governor's Council on Developmental Disabilities, the Iowa Health Care Association, and the Iowa Association of Homes and Services for the Aging.

The forums would not have been possible without assistance from community co-sponsors, who assisted with local logistics and publicity. A list of community co-sponsors is contained in Appendix A.

II. FORUM DESIGN AND IMPLEMENTATION

ICA sought to provide the opportunity to participate to Iowans throughout the State. Four sites were selected: Cedar Rapids, Des Moines, Davenport and Emmetsburg. Potential collaborating organizations were contacted, including area agencies on aging, AARP local chapters, senior centers, centers for independent living, community colleges offering CNA training, and Des Moines University. Local partners assisted in locating appropriate, accessible venues, and in some cases provided volunteers to serve as small group discussion facilitators. Publicity for the events was accomplished through the newsletters of local partners and through their local network of contacts. In the final week prior to the forums, AARP published ads in local papers. Radio and television stations were also contacted.

A major role for state-level and local co-sponsors was to assist in securing participation from as many members of key stakeholder groups as possible. In particular, ICA sought to reach out to direct care workers themselves, employer/service providers, and consumers. With financial support from the Office of the Long Term Care Ombudsman, a \$20 stipend was offered to the first ten direct care workers to register at each site. Included among consumers attending were many family caregivers, concerned about how they would be able to ensure on-going appropriate supports to their loved ones. Eight State legislators as well as representatives from Senators Grassley and Harkin's offices participated in the forums

The forums consisted of two segments, each lasting about one hour apiece. The first hour was devoted to a presentation on direct care worker issues in the context of broader issue of long term care. The audience was up-dated on the status of long term care reform efforts in Iowa. Brief presentations by direct care workers, on why they entered the field, the challenges and satisfactions their work provided them, and the kinds of supports that would make a difference in their ability to do the job, provided those in attendance with an insider's view of the issues.

The second hour was interactive, encouraging forum participants to think about and share their own values related to caregiving. A list of suggested values was developed in a large group session. The values expressed by different individuals were sometimes contradictory. Participants were then invited to join one of several stakeholder groups to continue the discussion: direct care workers, employer/providers, the elderly and their families and advocates, and people with disabilities and their advocates. (In Davenport and Emmetsburg the latter two groups were combined because of the small number of participants.) Participants in the small groups discussed how they are affected by direct care worker issues, and tried to identify the two or three values they regarded as most important in designing a cost-effective, consumer-responsive long term care system. Group facilitators tried to encourage input from everyone in their group.

Approximately 150 people participated in the forums. There was generally a good representation from the stakeholder groups regarded as key, although turnout of some groups at some sites was disappointing. It should be noted that a number of participants at each site chose to join small group discussions by other than their own constituencies.

III. RESULTS

Forum organizers were struck by the degree to which forum participants seemed engaged in the sessions — a clear indication that people had a strong personal stake in the issues. This is not surprising, given that those present were talking about their careers and livelihood, or the ability of their agencies to function on a day to day basis, or, in the case of consumers and family caregivers, fundamental quality of life issues.

Generally speaking, there were more similarities than differences in how people viewed the issues, both among the four locations, and within the stakeholder groups themselves. Over and over, small groups pointed to such powerful inter-relationships among values like personal dignity, a respectful working relationship, and overall quality of care, that it was often difficult for them to rank values in order of priority. However, a broad generalization can probably be made that both the elderly and disability constituencies placed the highest value on personal dignity and a respectful working relationship between the consumer of care and the Direct Care Worker, while both workers and employers looked at factors related to the quality of care and a safe working environment, such as training and manageable workloads.

Sometimes the different groups recognized the importance of a particular factor in ensuring a good caregiving system, such as worker competence, but would come at that issue from very different perspectives. For example, employers and direct care workers often expressed the view that consistent training should be provided to workers across all work sites, to ensure both a minimum standard of care and worker safety. The disability constituency in two forum sites, on the other hand, expressed the desire to see more consumer control in the training and instruction of workers, and for the worker's recognition of the consumer's capacity for independent action.

PRIORITY ISSUES

**Direct
Care
Workers**

Beyond wages, the safety of the Direct Care Worker and of the people they are caring for was an overarching concern which was reflected in comments regarding training and manageable workloads. :

- Wages and benefits.
- Manageable work loads / better staff: patient ratios.
- Safe working environment / training for the equipment we use.
- Proper and adequate training about the people we care for.
- Equality in training for like work, regardless of setting.
- Two way Golden Rule.
- Dependability / accountability.
- Recognition for care delivered.
- Flexible positive work environment to keep staff.

**Providers
Employers**

General comments centered on the preparedness of the Direct Care Workers for the quantity and diversity of the work they are asked to do.

- Professionalism that encompasses accountability, competence, mutual respect
- Safety, a concern from the top down, training for the worker and consumer, proper staff ratios, and risk management.
- It's important Direct Care Workers are part of the team and feel empowered. Need to create a positive, creative environment. Prepare for a person centered approach to care.
- Regulatory environment must support person centered care and respond to consumer choice.
- Standard training, based on an ethical standard, should be expected cross settings for similar work.
- Dependability starts at the top; administrators must set standards and support quality care.

**Family /
Advocates /
Elders**

The over-riding priority was dignity and respect for both the consumer and caregivers. Training and professionalism were seen as a foundation of respect.

- Adequate & ongoing affordable & Standards for care assure uniform preparation, regardless of setting, for like work accessible training for direct care workers.
- Equitable distribution of resources across care settings to increase access and assure preparedness of workers (rebalancing).
- Trust / Dignity: for the persons receiving and providing care.
- Need more access to end of life care / timely intervention/ and training for family caregivers.
- Access to information and clarification of definitions e.g.: "adequate staffing".
- Need flexibility and training specific to consumer needs in different venues.
- Professionalism – referring to the employer/ employee relationships & competence of caregiver.

People with Disabilities	<p><i>This stakeholder group discussed several issues having a bearing on a “consumer directed” model of care. People with disabilities have complex relationships with their Direct Care Workers upon whom they depend for health, safety and independence. The feeling was expressed that the caregiving system does not give credit to individual consumer’s capacity for independence.</i></p> <ul style="list-style-type: none"> • Respect and being treated with dignity are essential. Training of the worker is critical. • Concern that, due to worker turnover and low # labor pool, expectations for worker performance have been compromised. • Caregiving system should give credit to individual consumer’s capacity for independence. • Consumer control in the employment of workers.
Additional comments	<p><i>The priorities noted above were the 2-3 top priorities determined by the small groups across all four venues. However the issues noted below were also significant to forum participants.</i></p> <ul style="list-style-type: none"> • Training and ongoing continuing education needs to be meaningful and reflective of the needs of the client and their relationship. • Need increased flexibility in the CNA registry to allow cross site recognition for like work, and to recognize additional education and training. • Consumer advocates need to be active on issues that affect their loved ones. • Rights of the client as well as the worker need to be addressed. • Need to determine staffing levels. Language like “adequate” is too loose. • Desire positive media image of Direct Care Workers.

IV. POLICY IMPLICATIONS

Social change is often demographically driven; the abundance of new products and services for America’s aging, generally prosperous Baby Boomers are an obvious example. Demographics in the nation and in Iowa indicate there will be a rise in the demand for long term care services; even as they also make changes in the way services are delivered inevitable. People are going to expect and even insist upon choice. When people’s choices for long term care involve less expensive alternatives, policy-makers struggling with escalating State budgets are eager to find a way to respond. Boomers will also demand quality services more responsive to their families’ particular needs, such as skilled care for people with dementia.

Long term care is labor-intensive, and will remain so for the foreseeable future. While * 80% of long term care is provided by family members, a dependable, competent workforce must be available at the point where family caregiving is no longer possible or sufficient. Much of that work -- meeting the essential and extremely personal needs of millions of people in vulnerable situations--will be publicly funded. At stake are their lives, their happiness, and any prospects they have for maintaining independence and dignity. How to attract, train and retain a capable workforce is an absolutely critical question that must be answered.

Two compelling and not at all surprising interests surfaced at the ICA forums: recipients of care want to be treated with dignity, and direct care workers want to be treated like professionals.

* Source: US General Accounting Office. "Long-Term Care: Diverse, Growing Population Includes Millions of Americans of All Ages." GAO/HEHS 95-26. 1994.

The current system cannot always respond to those interests, for a number of important reasons. While examples of exceptional dedication and skill in caregiving abound, employer/providers cited frequent problems in recruiting candidates who have attained minimal educational levels and have a reasonable degree of sensitivity towards consumers. Quality care will not be available except through the provision of quality caregiving jobs which will attract and keep a large enough pool of qualified workers.

The values sought by the stakeholder groups at the forums illustrate the need for public policies which achieve the following objectives:

I. The re-enforcement of caregiving as a desirable and rewarding profession, through:

- Higher wages. While pay scales in Iowa's institutional settings show evidence of improvement, they will not remain competitive as the State's economy improves. If the State pursues significant rebalancing from institutional to home-based long term care, wages will have to be equalized across care settings to ensure an adequate workforce.
- Access to benefits, especially health benefits. Many direct care workers are their families' sole breadwinners. Lack of health benefits place such families at high risk.
- Adequate training and opportunities for on-going professional development. Concerns for consumer and worker safety must be addressed regardless of care setting, and adequate training is the safeguard most often cited by direct care workers and providers. On-going professional development helps workers to build new skills and take on new challenges in the workplace. The need for training is recognized by direct care workers themselves, their employers, and consumers, who say that dignity and respect in caregiving presupposes that the care is competently provided.
- Worker support and recognition. An example is ICA's peer mentoring initiative, which has provided workers with meaningful on-the-job support from experienced peers. Recognition can occur formally through events and awards, but the recognition most direct care workers seek consists of supportive attitudes in a healthy work environment.
- Opportunities for advancement. Direct care workers who presented at the forums were clear, that they do not regard caregiving as a stepping stone to other careers in the health profession. Rather, they seek opportunities to grow within the field of caregiving itself.

II. Ensuring a smooth transition to a long term care system offering greater choice of care setting and greater consumer control, by taking relevant workforce issues into account, such as:

- Ensuring ready access to a large enough supply of trained, available workers that consumers and providers can find and secure the services they need, and that workloads for direct care staff are manageable. Providers talk about difficulties in recruiting competent staff, workers talk about unmanageable staff/consumer ratios in the workplace, and consumers talk about the fear of losing access to care. Providing ready access to a trained workforce also assumes that there is a source of information on it — specifically, a current, complete and accessible registry.
- Ensuring consumers have access to information and assistance in becoming good employers, and creating safeguards for fair treatment of their employees. A shift to home and community based services and more consumer directed care *may* entail the hiring and firing by consumers of their own caregivers, maintenance of records

and compliance with labor laws. Consumers who lack the knowledge or skills to become good employers will suffer severe consequences, as will their employees.

- Helping to ensure consumer confidence that their care workers are adequately trained to meet their specific care needs, and that the safety of both consumers and workers is protected. Whether the training of care workers is highly standardized or tailored to the needs of individual consumers, all workers should be equipped with the knowledge and skills to provide care safely, in a manner responsive to consumer needs.
- Ensuring that wages and benefits for direct care workers are equalized across care settings. Rebalancing a long term care system cannot succeed without pay equity across care settings, which helps to ensure the flow of labor to the points where it is needed.

V. CONCLUSION

These public forums achieved their purposes of informing the public, securing Stakeholder input into direct care worker issues, and spurring participants to action. In general, forum participants seemed greatly interested and engaged. Based upon the participant evaluations, the forums were also effective in helping people clarify their own values related to caregiving, which almost universally proceeded from strong feelings about dignity and respect both for the recipient of care and the caregiver. Reports from small groups also showed that most people understand that the issues are complex, and that the values they expressed are highly inter-dependent. Dignity and respect, for example, was generally seen as dependent upon a sense of professionalism in the delivery of care, which in turn depends upon the competence and dependability of the workforce.

Finally, participants seemed to understand fully that the dialogue will continue, and that solutions to the direct care worker issues they regarded as so important will not come without persistence and hard work, by all who have a stake in them.

APPENDIX A: List of Partners and Community Co-Sponsors

The following State agencies and state associations assisted Iowa Caregivers Association with the forums:

- Iowa Department of Elder Affairs (Primary funding)
- AARP Iowa (Principal Co-sponsor)
- Iowa Office of the Long Term Care Ombudsman (Principal Co-sponsor)
- Iowa Department of Public Health – Center for Health Workforce Planning
- Governor’s Developmental Disability Council
- Iowa Health Care Association
- Iowa Association of Homes and Services for the Aging

ICA and its co-sponsors extend special thanks to former Governor Terry Branstad, and to participating members and staff representatives from the United States Senate and the Iowa Assembly:

- U. S. Senator Chuck Grassley
- U.S. Senator Tom Harkin
- Senator John P. Kibbie
- Senator Doug Shull
- Representative Swati Dandekar
- Representative Jeff Elgin
- Representative Marcella Frevert
- Representative Rob Hogg
- Representative Joe Hutter
- Representative O. Gene Maddox
- Representative Jo Oldson
- Representative Greg Stevens

The forums would not have been possible without the assistance of:

- AARP local chapters
- Aging Resources of Central Iowa
- Alzheimer’s Association – Quad Cities Branch
- Center for Active Seniors, Inc.
- Central Iowa Center for Independent Living
- Des Moines University – College of Osteopathic Medicine
- Evert Conner Center for Independent Living
- Generations Area Agency on Aging
- Hawkeye Valley Area Agency on Aging
- Heritage Area Agency on Aging
- Illinois/Iowa Center for Independent Living
- Iowa Lakes Community College
- Kirkwood Community College
- Northwest Aging Association



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