

**FAMILY MEMBERS OF PERSONS RECEIVING
NURSING HOME AND HOME CARE SERVICES**

REPORT OF FOCUS GROUP FINDINGS



June 2005



IOWA BETTER JOBS BETTER CARE (BJBC) COALITION

1117 Pleasant Street, Suite 221
Des Moines, IA 50309
Phone: (515) 241-8697
Fax: (515) 241-8587

Email: iowacga@aol.com
National BJBC Website: www.bjbc.org
Contact: Linda Simonton, Iowa BJBC Project Director

Funded through a 3 ½ -year, \$1.4 million grant from the Robert Wood Johnson Foundation and the Atlantic Philanthropies, The Iowa Better Jobs Better Care Coalition is a group of long-term care providers, workers, consumers, and policy makers that is working to reduce turnover among Iowa’s direct care workers. The members of the Iowa BJBC Coalition as of September 2004 are:

Iowa CareGivers Association, Lead Agency
AARP Iowa
Aging Resources of Central Iowa
Alzheimer’s Association, Greater Iowa Chapter
Center for Healthy Communities
Des Moines Area Community College
Direct Care Worker Advisory Council
Generations, Incorporated
Iowa Association of Area Agencies on Aging
Iowa Association of Homes and Services for the Aging
Iowa Commission on the Status of Women

Iowa Department of Elder Affairs
Iowa Department of Human Services, Bureau of Protective Services
Iowa Department of Inspections and Appeals, Health Facilities Division
Iowa Department of Public Health
Mid-Iowa Health Foundation
Northwest Iowa Community College
Office of the Long Term Care Ombudsman
Older Iowans Legislature
Lin Salasberry, Direct Care Worker
Southwestern Community College
University of Iowa College of Nursing Certification Center



IOWA CAREGIVERS ASSOCIATION (ICA)

1211 Vine Street, Suite 1120
West Des Moines, IA 50265
Phone: (515) 223-2805
Fax: (515) 226-3214

Email: iowacga@aol.com
Website: www.iowacaregivers.org
Contact: Di Findley, Executive Director

Founded in 1992, the **mission** of the Iowa CareGivers Association is “to enhance the quality of care through dedication to the direct care worker and all caregivers.” To accomplish its mission, ICA fosters partnerships between and among workers, advocates, providers, consumers, policy makers, labor, educators, and others committed to quality care. ICA has three main **goals**: 1) increase access to quality care for those who need it, 2) increase the number of caregivers, and 3) enhance quality of care. ICA’s focus is on four core **mission-driven activities**: 1) advocacy, 2) public awareness, 3) education, and 4) research and innovation.

TABLE OF CONTENTS

Executive Summary	3
Introduction	5
Methodology	7
Nursing Home Findings	9
Home Care Findings	26
Conclusions and Recommendations	38

EXECUTIVE SUMMARY

This focus group study, conducted under the auspices of the Iowa Better Jobs Better Care Coalition, with funding from The Robert Wood Johnson Foundation and The Atlantic Philanthropies, is a first step in obtaining the perspective of consumers (individuals receiving nursing home and home care services and their families) regarding direct care worker recruitment and retention issues. Two focus groups were conducted: one with family members of nursing home residents and one with family members of home care recipients.

The study's specific objectives are to:

- Determine family members' awareness and perception of direct care work.
- Identify skills, knowledge, attitudes, and personal qualities families require of direct care workers.
- Define outstanding and poor care provided by direct care workers.
- Determine the ideal relationship between direct care workers and family members.
- Identify family perceptions regarding training, certification, compensation, and benefits.
- Determine the potential for family members' advocacy regarding direct care worker recruitment and retention public policy and practice issues.

Because this is a small qualitative study, the information should be used to provide direction rather than draw definitive conclusions generalized to the entire population of Iowa family caregivers. Key findings from this study include:

- Awareness and acceptance of the term CNA appear to be high. The term "aide" is used synonymously with CNA and appears to have no negative connotations. In contrast, awareness of the term "direct care worker" appears to be low and may connote unskilled and uncertified.
- Certification is extremely important to families of individuals in both nursing home and home care settings. Certification implies testing against an accepted standard. It is important that the term "certified" be in the individual's title, along with what that person is certified to do, e.g. Certified Bath Aide, Certified Medication Aide, Certified Mentor. Certification is also linked to the perception of professionalism.
- Families articulated skills, attitudes, and personal qualities that they require from those providing personal care. In addition, they gave specific descriptions of both outstanding and poor care, what it means to be professional, and how family and paid caregivers can work together better as a team. This information will be beneficial in the education and training of direct care workers and those who work with them such as nurses, supervisors, and administrators.

- Communication (including participation in the care planning process) among those providing care and the family regarding the individual's condition and treatment is crucial to family members. There is room for improvement in this area.
- Families provided a range of viewpoints regarding direct care worker compensation, benefits, and ways to structure the system with pay incentives for increased education and skill.
- Family members are acutely aware of the direct care workers shortage because they have both observed and experienced it. They provided insights into the ways families may support direct care worker recruitment and retention initiatives.

A complete list of conclusions and recommendations is included on page 38 of this report.

INTRODUCTION

Background

- This study is conducted under the auspices of the Iowa Better Jobs Better Care (BJBC) Coalition through a 3-½ year, \$1.3 million grant sponsored by The Robert Wood Johnson Foundation and The Atlantic Philanthropies.
- The Iowa BJBC Coalition is a group of long-term care workers, providers, consumers, and policy makers that is working to reduce turnover among Iowa's direct care workers*.
- The Iowa CareGivers Association (ICA) is the lead agency for the BJBC Coalition.

*Direct care workers are Certified Nursing Assistants (CNAs), Nursing Assistants, Home Care Workers, and Personal Attendants who work in nursing homes, home care agencies, hospices, adult day centers, and hospitals.

Study rationale

- The Iowa BJBC Coalition and ICA have conducted several studies of direct care workers, supervisors, and nursing home administrators to investigate direct care worker recruitment and retention issues.
- This study begins to look at direct care workers from the consumer's perspective.
- The Iowa BJBC project defines consumers as both the person who is receiving care and the family members of those persons.
- At this time, the Iowa BJBC Coalition has the financial resources for a study of family members only. The persons receiving care will be surveyed when funding permits.

Purpose and objectives

- The purpose of this focus group study is to provide the basis for a quantitative survey of families of both nursing home residents and home care recipients to determine their expectations regarding services provided by direct care workers.
- The study's objectives are to:
 - Determine family members' awareness and perception of direct care work.
 - Identify skills, knowledge, attitudes, and personal qualities families require of direct care workers.
 - Define outstanding and poor care provided by direct care workers.
 - Determine the ideal relationship between direct care workers and family members.
 - Identify family perceptions regarding training, certification, compensation, and benefits.
 - Determine the potential for family members' advocacy regarding direct care worker recruitment and retention public policy and practice issues.

This report

- Most of the family members in both the nursing home and home care groups referred to the person receiving care as the "patient" and the caregiver as the "aide," so these terms have not been edited when families' own words are quoted.
- Families' own words are displayed in italics.
- The findings of this study as well as other studies conducted by the Iowa BJBC Coalition are available on the Iowa CareGivers Association website at www.iowacaregivers.org or by contacting the Iowa CareGivers Association at 515-241-8697 or information@iowacaregivers.org.

METHODOLOGY

The groups

Two groups were conducted for this study:

- Group 1, held on May 2, 2005 in Des Moines, was comprised of families of individuals who are currently receiving care in an Iowa nursing home or had received such care in the past year. Participants also had to have visited the nursing home at least four times.
- Group 2, held on May 3, 2005 was comprised of families of individuals who are currently receiving home care in Iowa or have received such care in the past year. Participants had to have been present at least once while the home care worker provided care.

The participants

- Group 1 was attended by eight female and one male participant.
- Group 2 was attended by 6 female and one male participant.

Use caution when drawing conclusions

- Because this is qualitative research, the findings from these focus groups are not intended to be generalized to the entire population of families of individuals receiving nursing home or home care services.
- The information obtained through this process should be used to provide direction, rather than to draw definitive conclusions.

FINDINGS: NURSING HOMES

FINDINGS: AWARENESS OF CNA AND DIRECT CARE WORKER TITLES

Awareness of title: CNA

- All family members are aware of the term CNA, think of it as synonymous with “aide,” and easily use the term CNA or aide in conversation.
- Most family members do not know what the letters CNA stand for.
- “Assistant” in the title CNA implies that this is the person who’s going to be doing the hands-on care. As one family member stated, “*Assistant automatically says to me, ‘This is the person who’s taking care of my family.’*”
- The word “certified” in the title is crucial to families because it indicates testing according to an industry standard and state regulation. Certification is important because, as one family member put it, “If we have to certify someone to apply chemicals to our lawn, we should certainly have to certify that someone is capable of caring for our loved ones.”
- One source of awareness of the term CNA is postings in some nursing homes that indicate to visitors who is caring for the resident that day, including the names of the nurses, LPNs, and CNAs. Family members indicated they like to be informed about the staff in this way.
- Several family members stated that it is difficult to tell the credentials of people working in the nursing home because they don’t always wear badges or identifying information and that this creates problems because they don’t know whom to go to for assistance with various questions or concerns.

Awareness of title: “direct care worker”

- In contrast to the high awareness and acceptance of the term “CNA,” only one family member had previously heard the term “direct care worker.”
- The term direct care worker suggests to these family members that this is the person who “*puts their hands on the patients,*” and does much of the work related to care, but that this is not a highly skilled job like that of a CNA.

**Awareness of title:
“direct care worker,”
continued**

*Direct care worker sounds like ‘maintenance worker’ – not skilled.
Direct care worker sounds like they’re trying to slip through the cracks of regulatory
certification so that they can be hired at a lesser salary with less training and less care.*

FINDINGS: AWARENESS OF CNAS’ WORK

**Awareness of CNAs’
work**

- Family members expressed awareness that CNAs provide direct personal care.
- Specific tasks that families mentioned were: bathing, lifting, answering lights, taking people to the bathroom, listening to peoples’ concerns day or night, walking people in the hall, using a gait belt, putting people to bed, motivating them, checking on them periodically to ensure their safety, doing group exercises to promote mobility, and celebrating holidays.
- Several family members indicated that brushing resident’s teeth is a CNA duty, but that it seems to be neglected, especially among residents with Alzheimer’s.

FINDINGS: CNA SKILLS AND ATTITUDES

**Skills and knowledge
required by CNAs**

Family members indicated CNAs need to know how to:

- Listen to and talk with the person they are caring for.
- Physically lift people to protect the person’s safety and their own.
- Help someone physically move and be able to communicate to the person being moved how to assist.
- Change a bed under a person.
- Use gait belt.

Skills and knowledge required by CNAs, continued

- Recognize basic medical conditions, report them appropriately, and follow up.
- Understand bowel habits of people who are confined.
- Understand medical terminology so that they can communicate with other members of the medical team such as doctors and nurses.
- Identify medical conditions that others won't see because the CNA is the primary caregiver.
- Follow through.
- Understand psychology.
- Get to know the idiosyncrasies of each person and take these into account when caring for them.
- Communicate with families about what the family needs to do related to their loved one's care.

Attitudes and personal qualities required by CNAs

In addition to the skills listed above, families also indicated that CNAs require the following attitudes and personal qualities:

- Attitude of respect. CNAs are providing very personal assistance such as bathing and incontinence care for people who may be embarrassed. CNAs need to understand this and be respectful. Families also indicated that CNAs need to see the individual they are caring for as a person who is worthy of respect.
- Patience.
- Empathy.
- Understanding.
- Sense of responsibility and commitment to the person they are caring for.
- Compassion.
- Enthusiasm - it's infectious and rubs off.
- Treat the individual not like a patient or resident, but like a person or family member.

Skills, knowledge, attitudes, and personal qualities required by CNAs: Selected illustrative comments

- *It's important to show respect for someone who is very vulnerable and not able to care for themselves and function as well. The aide needs to be able to communicate and do what needs to be done to meet their needs, but do it with respect as a human being as opposed to them being vulnerable and not being able to do a whole lot so it's just a matter of getting into the room and out of the room.*
- *The quickness indicates they're trying to be efficient, possibly short-staffed, but if they're doing it with respect for the patient they're doing it at a slower pace. It takes a while for any elderly person, especially in bed, to comprehend what's going on from one person going in and out of the room to the next. If they get in a hurry, yes, they're being efficient but from the standpoint of care, I think it's important that they have the respect of making sure that the patient understands why they're there, what they're doing, and what's going to happen next.*
- *It's important to celebrate holidays – it elevates spirits of the residents and the staff because they're having fun.*
- *Certain ethnic groups, Bosnians, for example, have brought with them from their culture an extended family process, level of dignity, and respect for the elderly. It's just part of them.*
- *It doesn't matter if you're a half-million dollar paid cardiologist or an entry level CNA. - the basic premise is the humanity that should show. Do they provide an appropriate amount of time for the patient, are they compassionate, and most importantly, do they want to get to know the patient?*

FINDINGS: OUTSTANDING CARE AND POOR CARE BY CNAS

Outstanding Care by CNAs: Selected Illustrative Comments

These are the responses family members gave in response to a question about what constitutes outstanding care by a CNA:

- *I get calls at home from the CNA saying, “Your mom really feels down tonight. I know it would be hard for you to come out right now, but I think if you just gave her a phone call, it would really perk her up.” That’s outstanding.*
- *Knows the person’s idiosyncrasies and jokes about them with the person in a very personal way.*
- *Tells me something my mom has done that day, something about Mom that’s pretty current, or a conversation they’ve been having. Even though Mom doesn’t really have conversations with people, she treats Mom as if they’re having a normal day-to-day relationship.*
- *I appreciate the CNAs who are feeding the people who really don’t want to eat and the time they take to try to encourage them. They try to feed them various parts of the diet so at least they get reasonable nutrition. They might have to feed two or three people at one table, but they keep the patients interested by funny conversation.*
- *Some CNAs, when they pass through activity areas near the nurses’ station area where a lot of people are, they just know who needs a hug, who needs to be comforted, who needs to sit up a little straighter. They’re just so tuned in. I really appreciate that.*
- *I wondered if anyone ever reads those forms we fill out when our loved one goes into the nursing home about their life, what they did in life, what they’re interested in. Maybe that goes to supervisors, but I think it would help if the direct care workers knew about it, too.*
- *I like memory boxes or posted bios so that everyone who comes there, including the families of other residents, knows about the patient’s interests so they can relate to them.*

Poor Care by CNAs

Families were then asked specifically what constitutes poor care by CNAs. These are their responses:

- Being in a hurry.
- Not answering a call light.
- Leaving the patient.
- Ignoring someone calling out.
- Not responding immediately when someone asks to be taken to the bathroom. As one family member stated, *“When he’s at least alert enough to say, ‘I’ve got to go,’ I think someone needs to be on it right away and at least give him that dignity.”*
- Sitting in the break room rather than looking for other ways to make patients’ lives better.
- Neglecting one’s own personal hygiene.

FINDINGS: HOW FAMILIES WANT CNAS TO INTERACT WITH THEM

How families want CNAs to interact with them: Selected illustrative comments

- *I like communication about how my parent has functioned that day.*
- *Knowing that when I’m at home, if there’s any kind of an issue, they know I’ll come if I’m needed and contact me. If there’s agitation or something that my being there with help with, to let me know.*
- *Communicate changes to me when he comes back from the hospital, for example, medication changes.*
- *Sharing personal information about what led the CNA into a career of helping others.*
- *Knowing that the CNA is developing a good relationship with my parent. I can tell that by the way they interact when they come in and out of the room.*

**How families want CNAs to interact with them:
Selected illustrative comments,
continued**

- *Communicating to me that there's been interaction with my loved one. Telling me what this day has been like for the person so I have an idea how to visit with her. For example, did she go to physical therapy today, did she dress herself?*
- *Voluntarily offer current information of interest to me without my having to chase them down and ask.*
- *Responding to requests that I've made, for example, her hearing aides.*
- *I appreciate staff who will initiate or at least be open to a feeling of partnership. That we're in it together caring for this person. For example, they'll say to me, "We really love these shoes with the Velcro closures because your dad just can't tie shoes any more and it's so quick and easy for us." And I do the same with them by asking, "Is there anything I can do to make it easier for you to accomplish this or that?" That really seems to work with the people who are open to it.*

Family and resident participation in care plan meetings

Several family members volunteered that they very much appreciate being included in care plan meetings and that this participation leads to better care.

- *In one instance, the family member had ongoing unresolved problems related to her mother's hearing aides that were solved once she participated in the care plan process and the hearing aides became an item in the care plan.*
- *Another family member said, "I love those quarterly meetings that that nursing home has. I just went to my first one for my dad and I thought it was fabulous! That, in addition to the caregiver calling me whenever there's a problem, keeps me updated. I find out if he's eating and can get a list of the meds he's on and why. All those things are really important to me and a really outstanding quality in where my dad is at. The direct care workers don't participate in the meeting, but the information comes from them."*
- *Another family member indicated that it's also important to make sure the resident themselves is aware of the information presented in the care plan meeting, because in her experience, that was not the case.*

How to resolve difficulties

Family members were asked what they do when there are difficulties between them and the CNAs providing care. Here are their responses:

- *I talk directly to the person. I've always found that works. I tell the CNA, "I don't want to talk to your supervisor, because I know you're most in touch with it." I've never had to go any higher.*
- *I asked them if I could put a white board up in my dad's room so that if there was something I thought they needed to know that I couldn't communicate before I left, I could put it on there. Little reminders. It made it easy and I don't have to worry if it got communicated from one shift to the next.*
- *It's a really tough spot because you're so emotional about it. It's my parent. When the incident happened with my dad and we couldn't find anybody and he's calling out, "I've gotta go to the bathroom," this incredible sense of urgency comes over you and you're emotional and you're not thinking very well and it's a very difficult spot to be in. You just really want to tell someone off because they're caring for your dad. You just have to take a deep breath and try to cool it. Emotions are so high.*

FINDINGS: CONTINUITY OF CARE

Importance of care by the same CNA: Family's perspective

Family members were asked how important it is to them (the family member) that the same CNA care for their relative each day. These are their responses:

- Seven of nine family members indicated it's "very important."
- Two said, "somewhat important." One of these family members indicated that if the person being cared for has Alzheimer's and doesn't recognize people, care by the same CNA might not be so important.

**Importance of care by the same CNA:
Resident's perspective**

Family members were then asked for their perception of whether their relative wishes to be cared for by the same CNA each day. Here are their responses:

- Four of nine family members indicated it's "very important."
- Four said it's "somewhat important." One of these family members stated that her mother is very friendly and knows all the caregivers so care by the same individual is not all that important.
- One family member (of a person with Alzheimer's) indicated that because of the Alzheimer's, care by the same person is, "not at all important."

FINDINGS: PERCEPTIONS OF CNAS AS PROFESSIONALS

**What is a professional?
Selected illustrative
comments**

- *There's difference between those who believe this is a career path and those who feel it's just a job.*
- *A professional provides a greater level of care: they **want** to go into that room, **want** to take care of the Depends or "accident." They know that there's a level of dignity that the person deserves and that as a professional, that's why they're in this profession. They have a greater level of listening and an ability to get to know the resident a little better.*
- *Considering people who are CNAs and who don't have aspirations to go beyond that, there are people for whom it's a job and people for whom it's a calling and they stay with it a long time and they really do become professional. They learn how to see a patient and become sensitive to signs and know there's something going on with that person. They treat the patient with dignity, they develop an intuition for when things are not quite right, they're sensitive to the fact that it makes so much difference to this patient if their favorite radio station is turned on when they go to bed. I certainly feel I'm dealing with professional people when I'm dealing with those people.*

**What is a professional?
Selected illustrative
comments,
continued**

- *It's all in the way they interact. They treat my dad like a friend. They don't take what he says personally. They're "with him," even though he's speaking gibberish. They're listening to him. They're trying to stay on the same page as he is.*
- *They're warm and friendly at the same time.*
- *There are two definitions of professionals. There is a nurse at the nursing home that no one likes. She is unhappy, negative, and has no patience about residents' slowness. To me, she's unprofessional acting, but she has a professional title of nurse. Then there are nursing assistants that act more professional than the nurse, even though they're not professional as far as education."*
- *Professionals show attention to detail. They notice the details about the person's life and how they like things done.*
- *I hate to hear them called "girls." Even the supervisors say, "I'll ask one of the girls." They've had training, they're not girls.*

Are CNAs Professionals?

- Family members were mixed as to whether CNAs are professionals.
- Based on the definitions of a professional listed above, families indicated that some CNAs fit the description of a professional, while others do not. Those that do not seem professional give the impression that they're simply "putting in their time."
- One of the family members who does not perceive CNAs as professionals said, *"My impression is that they're not professionals – they're people who are being paid a minimum wage; that have few other employment options, and are working this job until they can get something better."*

FINDINGS: CNA EDUCATION AND TRAINING

Perceived level of training currently required

- Family members were asked for their perceptions about how much education and training are currently required for CNAs.
- Most family members indicated they had no idea how much training was required.
- Families also indicated that because they don't know how much training CNAs have, they don't know what to expect from them.
- Those who did venture guesses about the amount of training said that it was probably very little training, that it would be less training than is required of people who work in hospitals, and that much of it was probably on-the-job training.
- One family member said, *"It's like McDonalds, those are entry level positions in the health care field."*

How much training and education *should* CNAs require?

- Without being informed what the actual training requirements are, family members were asked for their recommendations about the number of hours of education and training CNAs *should* receive.
- As with their knowledge of how much CNA training is actually required, most family members were uncertain how much should be required.
- Those who did express an opinion suggested the following requirements:
 - 1 week (because job performance has more to do with attitude than technical training)
 - More than 1 week
 - 6 weeks
 - 6-12 weeks
 - Training needs to include basic medical knowledge

**Reaction to 75 hour educational requirement:
Selected illustrative comments**

- *If it's for a CNA I position, then 75 hours is enough. But they need to do the job for a while, then get more education to move on to a CNA II, III, IV. That's how to ramp the system up to get people who are better trained and paid.*
- *So as not to make the shortage worse, have a smaller amount of required training and more emphasis on on-the-job training with supervisors to make sure the job is being done right. Then, give people the opportunity to move up.*

Is certification important?

- Family members strongly and unanimously indicated that certification is important.
- As one family member put it, *"It's imperative that aides be certified and licensed by the state so that you've got continuity going from one nursing home to another."*
- Another family member said, *"If the training and continuing education requirements could be increased during the CNA's career, then the pay could be commensurate with it because there is a direct correlation."*
- Some family members indicated that background checks should be required for certification.

FINDINGS: CNA COMPENSATION AND BENEFITS

What is CNA care worth?

Family members were asked for their opinion about what the care provided by CNAs is worth (without taking into account what the family is willing to pay for the care).

- All family members indicated, without being asked, that benefits should be part of the compensation package.
- Hourly pay recommendations ranged from \$10-\$20 per hour.
- That it should be a “livable wage” was brought up by several family members.
- These are family members’ specific responses:
 - *\$10-\$14/hour with benefits and the opportunity to work up. It’s not an entry level job.*
 - *\$11/hour plus benefits*
 - *\$15/hour plus benefits. I think it’s really important.*
 - *\$15-\$20/hour plus benefits*
 - *\$20. What they do is very important*
 - *Livable wage and benefits – de-stresses people in their lives*
 - *I don’t know an hourly amount, but it should be a livable wage and come with some benefits because benefits make life livable and make people feel more professional and part of the team. When there’s a distinction between staff that get benefits and staff that don’t, that lowers the expectations and sense of professionalism.*
 - *I’m out of touch with salary amounts, but it should be more than McDonald’s and have potential for salary increases as they stay with the work and for increased skills that they develop over that time.*
 - *I’m torn between wanting to pay a lot and knowing that I’m already paying a high amount for the care.*

How much would you be willing to pay for CNA care?

Families were then asked to consider not only what CNA care is worth, but what they as family members would be willing to pay.

- As before, all family members indicated that benefits should be included.
- One family member pointed out that it's not just what they personally are willing to pay, that it's a matter of public policy because much of the care is subsidized by taxpayers.
- Hourly rates ranged from \$10 to \$20 per hour.
- Here are family members' specific responses:
 - *\$10 with benefits*
 - *\$10-\$11. I think the work is really important, but to pay more than that, e.g. \$15, more education and training would be required.*
 - *\$10-\$14. Good initial salary and going up.*
 - *\$11 with health benefits and performance measures to grow their income.*
 - *\$11-\$14 with benefits and salary incentives to continue their education.*
 - *\$12 with benefits and the opportunity to progress with performance and further training.*
 - *Up to \$15 with benefits with potential for pay for performance.*
 - *\$15-20. Start at \$15 and full benefits at certification and then work up to \$20.*
 - *\$15-20 with benefits.*

Perception of the extent of health care coverage among CNAs

Family members were asked for their estimate of the percentage of CNAs that have health insurance coverage.

- Most family members said they had no idea.
- Those that did offer an estimate, suggested a range of 10-15% of CNAs with health insurance coverage. They based these estimates on an assumption that most nursing homes don't offer health insurance coverage and that CNA work is hourly and hourly workers aren't offered health insurance coverage.

FINDINGS: FAMILY MEMBERS' ROLE

Awareness of CNA shortage

- All family members expressed awareness, often based on their own observations at the nursing home, that there is a shortage of CNAs. As one family member said, *“It’s a revolving door.”*
- Here are some of their comments:
 - *It’s a tragedy. These people deserve so much more. One day, we’re all going to be in the same boat. If we don’t do something about it, it’s just going to continue.*
 - *I think the wages and lack of benefits are a reflection of our society’s lack of concern about a lot of these folks.*
 - *I noticed short staffing; I listen to conversations so I know they’re working many shifts in a row. They were doing their job... it wasn’t that they weren’t willing; they were exhausted.*
 - *They work very hard. It’s just constant, from one to the next to the next.*

Family members’ role in addressing the CNA shortage

Family members were asked what, if anything, they see as their own role in addressing the CNA shortage.

- The issue of growing problems resulting from the Baby Boom was mentioned by several participants.
- These are family members’ specific responses:
 - *Being there. Being an advocate.*
 - *Treat CNAs with respect. Encourage them. Show them respect for what they’re doing.*
 - *Serve on community action committees within the nursing home. You can be the intermediary between the patient and administration.*
 - *Needs a long range, global solution. Top down solution, if it’s to be a respected profession.*
 - *Take an interest in nurse patient ratio.*
 - *There needs to be state and federal recognition of what needs to change.*

Family members' role in relation to CNA care

Below are some selected illustrative comments regarding family members' role in relation to the CNA's care of their relative:

- *The kind of care my mother gets is directly correlated with how the aides are treated by me. In getting to know them, I've sensed a better sense of intimacy by recognizing them as part of a team. It's a matter of "What are **we** doing on Mom's behalf as opposed to what are **you** doing."*
- *Sometimes in the back of my mind is, "What happens when I leave? Is my dad getting the same care as when I'm there?"*
- *I don't know how people without advocates get by. If I wasn't there and an advocate for her, I don't know what would happen. For example, she had infection and the doctor's order for culture didn't get cultured. I had to threaten. Then, the x-ray didn't get done. I have to follow up and monitor her care. I have to find out what Medicare will pay for, how many treatments, etc.*
- *I think it's our responsibility to respond to the quality of care that's given our family members. I write a lot of "atta-boy" and "atta-girl" letters to the director with copies to the staff members about what I have observed or what my mother told me. Building the esteem of the CNA, when they know that the boss has seen this and it's coming as a result of the care they've given my mom, it reinforces that continuity of care.*
- *I've sat with my mom and helped her sign cards that she can give to her caregivers. Other times, when she's had a really good week because they seem to be on top of her care (it takes a lot to help her write this), she writes, "I really enjoyed how well my week went and what great care you all gave to me." On the different shifts, we've brought pizza or a Cheesecake Factory cheesecake. Just a tangible reminder, more than just words that, "You really do validate my mom's feelings."*
- *Whenever I talk with them, I say, "What's **our** plan for this week?" not "What are **you** going to do?" It's really important that the caregivers see you as part of their team and it doesn't put a huge burden on them to perform, because we're doing it together.*

HOME CARE WORKER FINDINGS

FINDINGS: AWARENESS OF TITLES

Awareness of titles

- Family members reported that the people providing in-home services for them have the following titles:
 - Nurses aide - 2
 - Home care aide - 1
 - Bath aide - 1
 - Health aide - 2
 - Caregiver - 1
- One family member was unsure of the exact title, saying, *“I just know they have some letters after their name, but I don’t know what they are.”*
- In conversation, family members used the term “aide” to refer to home care workers. Most of them use the term “patient” to refer to the person receiving services.

Awareness of title: “direct care worker”

- No one had previously heard the term “direct care worker.”
- When asked what comes to mind when they hear “direct care worker,” family members’ reactions were:
 - Anyone who touches the patient, does one-on-one work, does personal care like bladder/bowel cleansing.
 - *It could mean several things, for example, it might mean they **only** do things directly for the patient and don’t do anything else.*
 - *It doesn’t tell me anything. I would prefer that the title tell me what the person is capable for doing. For example, the title “Bath Aide” tells me the person gives baths.*
 - *The term “aide” is good because everyone knows an aide can only do so much.*
 - *A direct care worker could be a nurse or anyone providing hands-on care to the patient.*

Are direct care workers professionals?

- When asked if direct care workers are professional, these were their responses:
 - *Not necessarily...anyone can be called anything, but it still doesn't show me what you're capable of doing.*
 - *It depends who's giving them that title – if the state is giving them the title or if they're giving it to themselves.*
 - *I'd have to see their papers before I know if they're professional.*
 - *For direct care workers to be considered professional, they would have to be certified.*

FINDINGS: AWARENESS OF HOME CARE WORKERS' DUTIES

Awareness of home care workers' duties

- Family members volunteered the following when asked what duties home care workers perform: Bathing, dressing, personal care, shaving, housekeeping, laundry, respite, walking with the person, instructing the family in care and mobility such as how to do range of motion and how to walk the person.
- One family member indicated that home care workers will only do things for the patient, not the patient's family.
- Family members expressed awareness that nurses and aides provide different levels of service.
- There was some frustration that aides cannot do certain things, such as cutting the person's nails.
- Cost is an issue for some families. In order to have certain tasks performed, the person must have a nurse as well as an aide. Some families find the nurse too expensive so they elect to do more tasks themselves.

FINDINGS: HOME CARE WORKER SKILLS AND ATTITUDES

Skills and knowledge required by home care workers

- Family members indicated that home care workers need to be able to:
 - Provide stimulating conversation of interest to the person as well as show an interest in what's going on in the world.
 - Be physically strong and flexible.
 - Coach and motivate patients to do required activities that he or she may not want to do.
 - Display good housekeeping skills.
 - Lift and transfer safely (for both themselves and the patient).
 - Make a bed.
 - Help the person walk; use a gait belt.
 - Assess what the person needs.
 - Use “people” skills.
 - Adjust their care according to each person's needs (ability to “shift gears” every two hour shift).
 - Present a good personal appearance and have good personal hygiene.
- Family members did not spontaneously bring up medical knowledge. When asked about this, they indicated they had not mentioned it because they just assume that aides have medical knowledge, including understanding disease processes, knowing how to work with someone with dementia, observing skin breakdown, and knowing when to contact a nurse.

Attitudes and personal qualities required by home care workers

In addition to the skills and knowledge listed above, family members stated that home care workers require the following attitudes and personal qualities:

- Patience.
- Willingness to take time with the patient.
- Show interest in the patient.
- Treat the individual with respect because they're still a person.
- Be personable, pay attention to the person.
- Be friendly; say "hello" to the family when they enter the house each day.

FINDINGS: OUTSTANDING CARE AND POOR CARE BY HOME CARE WORKERS

Outstanding care by home care workers

Family members were asked to specifically describe what constitutes outstanding care by a home care worker. These are their responses:

- *My husband, who has had a stroke and knows what he wants to say but can't get the words out, was having a bad day. She sat there very patiently and tried to get him to express what his problem was. She was there past her time and she definitely wanted to help him. It was outstanding because she was working so hard with him.*
- *You can bring in the meds, but it's a whole different thing if you sit and talk and visit and spend time and are compassionate.*
- *Many people can't hear. It's outstanding if a caregiver will speak up so people can hear and understand what they're saying and make sure they understand it by asking them again, "Do you understand?"*
- *Compassion is so important. How do you certify that?*
- *She cheered up my wife and got her laughing.*

Poor care by home care workers

Family members were asked what constitutes poor care by home care workers. These are their responses:

- *Showing an attitude of having a chip on their shoulder; acting like they resent their time there.*
- *The aide sits in her car for 15 minutes before she comes into the house and then she sits in the chair for 15 minutes after she finishes the bath. She's always so tired.*
- *They provide a schedule at the beginning of the week, but they don't necessarily stick to it. If anyone is on vacation, the schedule gets switched around. Or, like today, when the aide got there, she said she had to leave an hour early. Mom likes to have her bath in the morning, but that may not happen.*
- *Not using latex gloves.*
- *Speaking to the family as if the person isn't there (much agreement). It's terrible when that happens.*
- *Impatient, "in and out", incomplete care*
- *Bath aide who didn't know how to give a bath*
- *Every worker that my mom has had took up my mom's allotted time by sitting there and doing her paperwork (much agreement). They should go back to the office to do their paperwork.*

FINDINGS: HOW FAMILIES WANT HOME CARE WORKERS TO INTERACT WITH THEM

The ideal relationship between the home care worker and family members

Family members were asked to describe the ideal relationship between them and the home care worker. These are their responses:

- *Mother tells me ways that she wants things done. I appreciate it when the caregiver takes that in and keeps it there and you don't have to tell them the same thing every day. There are so many little things that irritate people and the caregivers don't know it.*
- *She respected what we wanted her to do instead of just ignoring us and doing things her own way.*
- *Aides should not talk about their personal problems (much agreement).*

Importance of communication between home care workers and family members

All family members agreed that communication between the home care worker and the family caregivers about the person's condition and treatment is crucial. Here are some of their comments:

- *I want them to say hello when they come in, ask me how she's doing and is there anything new today, and take it from there, rather than just walking in and not saying anything.*
- *They should at least touch base when they get there to find out if anything has changed because they could have fallen or not slept well during the night. When the aide is done, she needs to touch base with us again and let us know if anything is out of the ordinary, for example, swollen feet, bruises they notice when bathing her.*

Importance of communication between home care workers and family members, continued

- *Sometimes they get defensive. When you ask questions about your relative's care, they shouldn't take it as criticism, but as concern.*
- *The aide would call me and complain about my father's behavior (he has dementia). In my opinion, she should have understood that this was part of the disease.*
- *Communication from the aides to us was poor. One aide was going to keep a journal so we would know what was going on because we weren't there. It didn't happen, but it would have been a good thing to keep the communication open – so we would know what was going on and how he was doing.*

FINDINGS: CONTINUITY OF CARE

Importance of care by the same home care worker: Family's perspective

Families were asked about their own perception of the importance of consistently having the same home care worker. All indicated that consistency is very important. Here are some of their comments:

- *One of the reasons it's important to me to have the same aide is that if I've had the same person for a couple weeks, then I feel like I can be gone while they're there because I'm familiar with them and trust them with my husband.*
- *It's important to be able to trust the person who's in your house.*
- *She's more comfortable if she has the same person. If she's comfortable, then I'm comfortable.*
- *We're supposed to have care for an hour, but we rarely get that. We have to be careful though, because we like the aide we have and some of the others didn't work out so well. So, we forgo the whole hour of care so we can keep this aide.*

Importance of care by the same home care worker: Person's perspective

Family members were asked about the importance to their relative of having the same aide each time.

- Most indicated that their relative strongly prefers consistency.
- *He doesn't like all these strange people in his house. They don't send the same person each time. He said, "I don't like someone coming in here and giving me a bath that I don't know."*
- One family member indicated that her mother likes interaction with different people. *She's a little "iffy" about them the first time they come, but after that she's fine. It's probably more important to me to have the same person than it is to her.*
- *One of the reasons my mom decided to give up home care and leave the care to me was the lack of consistency – they were never there at the same time and it was always a different person. Also, training was lacking.*

FINDINGS: PERCEPTIONS OF HOME CARE WORKERS AS PROFESSIONALS

Are home care workers professionals?

- *There's a difference between professionalism and being documented. A person who has done this work their whole life would have a degree of professionalism, but it might not be documented (certified).*
- *Someone who is really good at something could be considered a professional, even without documentation.*

FINDINGS: HOME CARE WORKER EDUCATION AND TRAINING

Perceived level of training currently required

Family members were asked for their understanding of how much training is required for someone to become a home care worker. These are their responses:

- 100 hours to be a CNA
- 6 weeks or less to be a CNA
- 2 years to be certified
- 18 months to be certified (two responses)
- The training is ongoing to keep up their license
- No special training to be a bath aide
- Don't know

Is certification important?

Family members were asked if certification is important for home care workers. These are their response:

- Very important – 3 responses
- Somewhat important – 3 responses
- Not at all important for a bath aide - 1 response

What should certification be based on?

The following are family members' thoughts about what certification should include and how it should be administered:

- *It should include schooling, actual hands-on learning, demonstration of skill, and on-the-job training.*
- *There should be a state-approved standardized test. Right now, it seems like each agency has its own criteria. These should be standardized. (All participants agreed with this.)*
- *I think it should be set up just like insurance companies. Every insurance company is required to follow the same regulations monitored by the state.*

What should certification be based on?
continued

- *There needs to be some kind of guarantee that you will get what they're telling you you're going to get in terms of capability of the person coming in.*
- *They need to re-evaluate the positions. Even a bath aide should have more skill than just a family member giving them a bath. A health aide should at least be able to read and take a blood pressure.*
- *To be certified, there should be a basic level of skill that each level meets and it should be standardized.*
- *If you're just hiring a homemaker to come in and clean, they shouldn't have to be certified – it depends on what you're hiring the person to do.*
- *Background and reference checks should be included in the certification process.*

FINDINGS: HOME CARE WORKER COMPENSATION AND BENEFITS

What are home care worker service worth?

- These are the hourly rates that family members indicated home care worker services are worth (as opposed to what they as family members would be willing to pay):
 - \$10.50
 - \$10-\$12
 - \$12, at least
 - \$12; For 24-hour care, \$150/day
 - \$15-\$25, depending upon what they're doing
 - \$25
 - \$25 because it makes my wife happy and I feel comfortable with them.
- None of these family members mentioned benefits.

How much would you be willing to pay for home care worker services?

These are the hourly rates that family members said they personally would be willing to pay for home care worker services:

- \$10-12 - 6 responses
- \$25 – 1 response

Perception of the extent of health care coverage among home care workers

- Family members were asked what percentage of full time agency home care workers are covered by health insurance. These are their estimates:
 - 90% - 3 responses
 - 80% - 2 responses
 - 60% - 1 response
 - No idea – 1 response
- Family members were then asked how many people who provide home health services independently are covered by health insurance. These are their estimates:
 - 10% - 1 response
 - 20% - 2 responses
 - 40-50% - 1 response
 - No idea – 3 responses

Reaction to statistics regarding health insurance coverage

These are family members' responses when informed of the actual percentage of direct care workers who have health insurance coverage:

- *I think it's pathetic that anyone doesn't have health care coverage.*
- *Employers don't want to provide coverage.*
- *One girl that comes to the house works for the health care insurance.*

FINDINGS: AWARENESS OF HOME CARE WORKER SHORTAGE

Awareness of home care worker shortage

- Family members indicated that they are very aware of the shortage because they have experienced it.
- One family member said that the shortage occurs because people don't want to work with old people.
- *It doesn't pay enough. If they paid more, they'd get more qualified people.*
- *The agency takes in \$30-40 per hour and they pay their aide \$9 per hour. The aides know that and it's degrading to them to know that the agency makes 3-4 times what they do.*
- *One of the reasons they have to charge so much is all the regulations and paperwork they have to deal with. They have as many people in the office as they do in the field.*

CONCLUSIONS AND RECOMMENDATIONS

Conclusion 1

- Awareness of the title CNA is high among these families of nursing home residents. The term “aide” is used synonymously with CNA. “Aide” implies the person who provides personal, hands-on care and does not appear to have negative connotations.
- In contrast, there is low awareness of the term direct care worker and it appears to connote a lack of skill or certification.
- It appears to be important that the title convey what the individual is qualified to do e.g. bath aide indicates the person is skilled in giving baths.

Recommendation 1

- Consider these findings when determining the titles for the various personal care jobs.
 - Re-evaluate whether to use the term “direct care worker” when communicating with consumers.
-

Conclusion 2

- Families of people in nursing homes and receiving home care services may be unaware of the various job titles (CNA, nurse, bath aide, supervisor, administrator) and what each person does. This is of special concern when family members have questions and are not certain who can answer them.

Recommendation 2

- Promote the practice currently in place in some nursing homes where the titles and names of the individuals caring for each resident that day are posted.
 - Consider expanding this to include a posted listing of whom to go to for various types of questions or concerns.
 - Assure that staff wear name badges at all times that indicate both their name and title.
-

Conclusion 3

- Families of both nursing home residents and home care clients identified the skills, knowledge, attitudes, and personal qualities that they require in those providing personal care.
- In addition, families offered explicit descriptions of both outstanding and poor personal care.

Recommendation 3

- Use these recommendations to develop and expand education and training for direct care workers as well as the supervisors, administrators, and others who work with them.
-

Conclusion 4

- Families strongly desire good communication between themselves and those providing care, particularly regarding any changes in the individual's status and information the family may need as they provide care.
- In home care settings, communication with the family regarding the person's condition and care is especially important because family members may not be present when the care is given, yet they may be heavily involved in the person's care.

Recommendation 4A

- Assure that nursing homes and home care agencies address in their policies the communication with families.

Recommendation 4B

- Provide education and training regarding communication with families for direct care workers, supervisors, and administrators.

Recommendation 4C

- Disseminate this finding to nursing homes and home care agencies. Encourage them to engage families in brainstorming creative ways to improve communication with families such as the white boards in the rooms or the home care journals suggested by the families in this study.
-

Conclusion 5

- Families in this study very much value participation in the care planning process by both the individual receiving care and the family. The input of the direct care workers is also seen as important since families are aware that they have the most personal contact with the individual.

Recommendation 5

- Disseminate this finding to nursing homes and home care agencies and encourage them to develop or continue ways to involve both the individual receiving care and their family in the care planning process.
-

Conclusion 6

- It appears that having the same person care for the individual each day is important to most family members, both in nursing homes and home care settings.
- For most of the people receiving care, it also appears that having the same person provide care is important, however, there seem to be a few individuals who do not mind or may actually prefer being cared for by several individuals, all of whom they know.

Recommendation 6

- Proceed on the assumption that families and individuals prefer care by the same individual and structure services to accommodate this because it appears those who accept or prefer care from a variety of individuals are likely the minority and likely won't be put off by consistent care from the same individual.
-

Conclusion 7

- Lack of a consistent schedule and a schedule that is followed appear to be issues for home care recipients and their families.

Recommendation 7

- Continue efforts to provide consistent scheduling and adhere to it.
-

Conclusion 8

- Families cite behaviors that are professional and indicate that those with professional titles may not act professionally.
- Families also draw a distinction between people who are in the field because it's a calling and who are skilled at what they do (those people are professionals regardless of their title) and people for whom it's just a job.
- When direct care workers are referred to by their supervisors and co-workers as "girls," this is perceived as belittling direct care workers' skills, education, and professionalism.

Recommendation 8

- Include these findings regarding professionalism in the education and training of direct care workers as well as those who work with them such as nurses, supervisor, and administrators.
-

Conclusion 9

- Families in both nursing home and home care settings indicate that it is extremely important for direct care workers to be certified.
- Education for certification includes classwork, hands-on training, and on-the-job training.
- Certification means the individual has met standardized criteria and passed a test.
- Education includes training on the specific health conditions that their family member may be experiencing and how this condition affects needed care.
- The state government is seen as the entity to oversee this certification.
- Families indicate that professionalism and certification are linked.

Recommendation 9

- Continue efforts to assure standardization of practice and certification of direct care workers.
 - Consider putting the term "Certified" in each title that receives certification, e.g. Certified Medication Aide, Certified Bath Aide, Certified Mentor so that families know what the individual is certified to do.
-

Conclusion 10

- Families in this study articulated a range of figures regarding what direct care workers services are worth.
- Some are torn between valuing the service highly and an awareness that they are already paying a good deal for services and may not be able to pay more even though they value the service.
- In home care, there may be an expectation to pay less for the service if paying out-of-pocket versus receiving some form of government payment for the service.
- Many families also indicated that there need to be opportunities built into the system so that direct care workers with increased education, training, and experience can receive more pay.
- Many families indicated that benefits are a key element in direct care worker compensation.

Recommendation 10A

- Utilize this information to assist in determining compensation and benefits for direct care workers.

Recommendation 10B

- Continue efforts to develop a system of incentives in which direct care workers who receive more education, training, and experience can move up and receive more compensation.

Recommendation 10C

- Continue efforts to expand the number of direct care workers who have benefits such as health insurance.
-

Conclusion 11

- Families are aware of the direct care worker shortage because of their own observations and experience.

Recommendation 11

- Determine ways to engage families to address the practice and policy issues related to the direct care worker shortage.
-

Conclusion 12

- Families articulated a desire for a partnership with direct care workers in providing care and suggested ways of doing this.

Recommendation 12

- Determine ways to bring family and paid caregivers together to provide care.
-