

THREE FOCUS GROUPS WITH HOME CARE AIDES:
A QUALITY ASSURANCE PROJECT

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EXECUTIVE SUMMARY

Concerned with improving the quality of services provided under the Home and Community-Based Services waiver by their contractual network of home care agencies, a group of Area Agencies on Aging (AAAs) have embarked on several quality assurance activities. One of these efforts was a series of three focus groups with home care aides, led by consultant Ronald Eggleston. Aides provide most of the services under the waiver. The purpose of the focus groups was to gather information to help improve the recruitment, training and retention of these aides, who are so critical to the overall waiver program.

The sessions were held in March and April 1999, in Lansing, St. Joseph and Escanaba. There were 28 participants, one of whom was male. Their ages ranged from 18 to 67, and their home care experience ranged from 9 months to 32 years. Fourteen had work experience in nursing homes, and only 9 had health insurance through their work.

The facilitator led discussions following a script designed to draw out responses about the interaction between the aides and the service user and his/her family. There were also questions about aide training and organizational support, including job benefits, as well as aides' perceptions of the AAAs. Aides were asked about their job satisfaction and involvement in the shaping of care plans. Finally, they were asked about their future career plans and any suggestions they had for improving the work situation.

SESSION RESULTS

Aides state that their work is personally rewarding. They get satisfaction from seeing someone's condition improve under their care, or from allowing a person to avoid nursing home placement. They liked becoming like "part of the family," and felt a sense of personal growth. Some comments illustrate their feelings: "It is not just a job. You share your caring, your compassion. Things that are important to other people." "When I am working with my patients, I forget my own problems. We are helping each other. I gain a lot from that." "I don't think of it as my job. I think of it as going to visit my friend." "With this job, I feel I have a purpose in life."

When asked about the difficulties or challenges of the job, several of the aides chose to look at things from the perspective of their clients, not themselves. For example, they were concerned about limits in program expenditures that could limit the hours of service available to needy persons. Some also expressed concern about those times when a person can no longer be cared for at home, or

when a person with dementia no longer recognizes them. A few aides said they feel the stress of caring for persons with dementia, when the constant repetition of stories or the paranoia becomes evident. Overall, however, they show a patient understanding of the condition.

There were several issues related to interaction with service users' families. Often families do not understand how ill or frail their loved one is, leading them to resent the presence of paid caregivers. Admittedly, some people take advantage of the situation: "Sometimes you find you are working for four or five people, but you are getting paid for just one." More often, the family members may try to do too much, given their own health and emotional problems. The aide can let them ease back on care and tend to their own health. Aides are fully aware of their vulnerability in the home setting, but quite stoic in their acceptance of that as part of the job. They put up with verbal abuse and even racism, letting it "roll off their back" as they go about their work.

Successful aides learn how to balance all the pressures on them, so they can do what they have to do. They have to draw the line between being a friend and a paid caregiver. They have to deal with conflicting demands in their workplace and even at home. Often, it seems there is not enough time to do all that is necessary. In those cases, aides stay beyond the assigned hours: "I just couldn't leave until the job was done."

Not all aides get the same training from their agencies. There appears to be quite a variety in the nature and rigor of the training of new aides. Also, not all agencies have regular in-service training sessions, where all staff is required to attend and is paid for doing so. Along the same lines, agencies do not have uniform supervisory practices. Not all new aides are supervised on-site during their first visits to a person, and for veteran aides, some agencies do more supervision by telephone than by on-site visits. Aides think they could provide some valuable input into the process of deciding what types and amounts of care persons should get, but not all of them feel their ideas are listened to (at least not without persistent pushing on their part).

Most of the time, aides are working with their clients, and they have little or no opportunity to interact with other aides. This does not allow them to share with others their experiences, frustrations or doubts. They have to rely on their own judgment nearly all the time, and this can be difficult.

Aides show some confusion about the role of the AAAs. Several aides said they could not understand how amounts and types of services were determined for the persons they cared for. Some care managers have succeeded in making themselves known to aides, and that is a positive factor. There are also general positive feelings toward the AAAs because they have made the home care waiver program possible in the areas served.

All of the 28 aides expressed their intent to remain in the home care field. Some of the statements that best summed up the aides' feelings about the job were: "The ones who can do this work should keep at it. It is rewarding work." "This is the best job I ever had. I do wish there were more benefits, even for part-time people."

When asked for suggestions to improve the job of a home care aide, most aides thought there should be higher pay, to recognize the importance of the work they do and the risks and effort required to do it. They also think higher pay will ensure that more people enter the field. Incentive pay for longevity or outstanding performance was also cited. Aides also thought there should be such benefits as health insurance, and there should be a redefinition of "full time" to mean less than 40 hours per week. (Many agencies limit benefits to only those at the 40-hour level). The most frequently suggested improvement was "better communication" (variously directed to relations between the AAA and the home care agency, the home care agency and the aide, and the aide and the family). Having a clearer idea of what is expected by all parties would improve the job.

CONCLUSIONS

Home care aides provide most of the services under the Home and Community-Based Services waiver. It is essential that the home care agencies recruit, train and retain quality staff. The persons who participated in the focus groups demonstrated commitment, concern and caring. Their dedication to the job of home care was impressive. The best aides are not motivated by financial considerations, but that does not mean that pay and fringe benefits are unimportant to them. Major changes in the rates paid for aide services (personal care, homemaker and chore services) can only come from the state level. Nonetheless, home care agencies and AAAs can improve the situation for home care aides. Home care agencies must do a better job of training staff, supervising them, giving them clear feedback, and giving them opportunities to interact for learning and morale purposes. The AAAs can play a key role in working with their contract agencies to improve communications and raise standards of quality. Special attention should be paid to the area of client or consumer choice in the daily routines of care.

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BACKGROUND

In Fiscal Year 1997-98, a consortium of three Area Agencies on Aging (Tri-County Office on Aging, UPCAP, Inc., and Region IV AAA) received a Technical Assistance Grant from the Michigan Offices of Services to the Aging. The purpose of the grant was to help AAAs prepare for managed long term care (LTC). The AAAs concentrated their efforts on two areas: learning as much as possible about managed LTC care in other states, and improving their own operations under the Home and Community-Based Services Waiver for the Elderly and Disabled.

A major component of the second focus was improving feedback from waiver consumers. A consultant, Capitol Research Services, Inc., was hired to conduct focus group sessions with waiver recipients and their family caregivers. In three sessions, one at each AAA, a total of 9 clients and 24 caregivers expressed their thoughts and opinions about the waiver program and the role of the AAAs. While the overall findings were quite positive, there were some comments about the quality and proficiency of home care aides that drew the attention of the AAAs. Since aides provide the majority of services under the waiver, it is crucial that quality be assured for their activities. Consequently, when the opportunity arose under a second TA Grant for Fiscal Year 1998-99, the consortium (now expanded to six members) decided that improving the quality of services was a very high priority. In particular, the AAAs wanted to improve the recruitment, training and retention of effective home care aides. Since focus groups proved useful before, the AAAs decided to use this qualitative approach with home care aides to obtain their input, with a session at each original consortium member's home office.

RESEARCH METHODS

Ronald Eggleston, an independent health care consultant under contract with the consortium, conducted the focus group sessions. The participants were selected from lists provided by home care agencies in response to a solicitation letter from an AAA, explaining that the waiver agency was interested in gathering information to improve program operations. At the sessions, participants were asked to fill out a basic information sheet that provided data on age, work experience and benefits received. In all, 28 aides were involved.

At the Tri-County Office on Aging (TCOA) in Lansing on March 11, 1999, there were eight participants (out of ten who had agreed to attend). While six agencies provided names, aides from four agencies were able to attend the session. The participants were all women and white, except for one African American. Their ages ranged from 28 to 68. They reported their home care experience as: 11 months and 1.5, 2, 3, 4, 8, 13 and 15 years. Five have worked for just their current employer, while two worked at one other agency and one at two others. (In addition, one aide stated she did fill-in work for other agencies). Two reported experience working in a nursing home. Only two reported that they had retirement benefits, while one had dental coverage and one had health insurance. When asked about the numbers of persons currently served in a typical week, they responded: 1, 2, 3 (2), 4, 6, 8-10, and 10-12.

The session at Region IV Area Agency on Aging was held on March 24, 1999 at the office in St. Joseph. Again, 10 aides agreed to attend and eight showed up to participate. They worked for five different agencies. This group was all women, three of whom were African American. Their ages ranged from 40 to 67, and their reported home care experience was: 2 (2), 3, 6, 10, 11, 15 and 32 years. Two had worked only for their current agency, while 6 had worked for other agencies. Three reported prior nursing home experience and two persons had health insurance (and then only if they worked enough hours in the week to qualify). The aides currently served 1 (3), 2 (2), 3(2) and 10 persons in a typical week. Of note, four aides each reported that they had served over 100 persons in their career to date.

The session at UPCAP was held on April 28, 1999 at the Escanaba office. There were 12 aides representing six agencies, with 11 women (one African American) and one man. The ages ranged from 18 to 57, and their reported home care experience was: 9 months (2), and 1+, 1.5, 2, 3 (4), 4, 7, and 8 years with their current agencies. None had worked for other agencies, although 9 had worked in nursing homes and three had done home care on a private basis. Half of the group had no benefits, while six had health insurance (and two of them had a retirement plan). In a typical week, the aides reported serving 1 (2), 3 (2), 4 (2), 5 (3), 7, 10, and 12 persons; one aide had served over 75 persons and another over 100 in her career.

The facilitator led the discussion following a script (see appendix) designed to draw out responses about interaction between the aide and the consumer and his/her family. In addition, there were questions about training and support, including job benefits, and the aides' perceptions of the AAA. The script was designed following research into the issues of home care provision, with special attention given to the aides' expressions of job satisfaction and sense of involvement in the development and execution of care plans. The sessions lasted from approximately 90 minutes to two hours and were tape-recorded with the knowledge of the participants. At the end of the session, the participants

were paid a \$30 honorarium. At one site, an aide who got lost and arrived late was given \$20 and sent home without participating.

STATEMENT OF LIMITATIONS

The focus group is a qualitative research tool. The participants are not selected randomly, so they do not represent the universe of home care aides. It was necessary to request the cooperation of the home care agencies to secure the lists of potential participants. Two agencies simply provided participants, while the others gave choices. Obviously, they selected their “best” people, those with a positive job attitude, willing and able to express their opinions. Some of those contacted initially could not make the scheduled time, so no fixed selection pattern was used with the lists of names. Two other subjective factors must be cited: the impact of a group on responses (as opposed to answers given in one-on-one interviewing) and the possible tendency to “tell them what they want to hear.” In this series of focus groups, positive responses about the rewards of home care vastly outnumbered any negative comments. As the facilitator, I judged these responses to be sincere and heartfelt, not artificial.

Given the dynamics of group discussion and time constraints, it was not possible to ask the same questions in the same way in each group. Some questions were combined in the interest of time, or to avoid repeating a topic raised by responses to a prior question. Also, in the summaries of the sessions, responses were placed with the topics they fit best, rather in their exact occurrence in the session. Finally, the abundant quotations cited in this study are sometimes paraphrased or grammatically modified, but every effort was made to capture the “flavor” and meaning of the original statement.

Despite various limitations, focus groups can provide insight into an issue or set of activities. This is especially true if the attitudes or observations expressed tie into other, relevant research. Many issues raised by the home care aides did in fact resonate with the results of other research, both in Michigan and nationally.

RELEVANT RESEARCH

In the summer of 1998, Capitol Research Associates, Inc. conducted focus groups in each of the three communities that were sites for this study. Users of waiver services and their family caregivers were involved in these three sessions, which asked a series of questions about the waiver program, the role of the AAAs and the performance of waiver providers. While the overall findings were quite favorable to the waiver, the AAAs and the providers, there were some statements that drew the concern of the AAAs. In particular, there were some comments that not all the home care agencies were of equal quality, that some workers were not well trained or supervised, and that there were some poor “fits” between aides and consumers. Consequently, some questions to probe into these areas were built into the script for the focus groups with home care aides.

The Fall 1994 issue of *Generations*, The Journal of the American Society on Aging, was devoted to the topic of "Frontline Workers in Long-Term Care." Several of the articles discussed research that bears on this focus group project. Penny Hollander Feldman (pp.5-10) noted that paraprofessional work (health care aides) in nursing homes and home care agencies is the fastest growing occupation of the 1990s. Percentage-wise, in-home care is the fastest growing segment of this field. Feldman listed the rewards of aide work: (1) warm personal relationships between caretakers and the clients; (2) a sense of personal responsibility, pride and accomplishment that comes from serving those in need; (3) the opportunity for personal growth, through confrontation of such life issues as power and control, disabilities and dying; and (4) the chance to develop clinical expertise based on intimate knowledge of individuals. On the other side of the coin, Feldman listed the challenges of aide work: (1) wages are lower for nursing home aides than for persons doing similar "bed and body work" in hospitals, and home care aides get paid less than nursing home aides; (2) assuring the well-being of clients imposes on the aides both the physical burdens of hard work and the ethical challenges of assuring the client's well-being; all of this is done often with inadequate training and support, while isolated from peers and the care-planning process; (3) there are inadequate opportunities for advancement in the aide field. The end result of this situation, according to Feldman, is high job turnover, which in turn impacts the quality of long term care. Quality of care requires standards of care, service stability and service continuity. This is evident in client satisfaction surveys.

Donna Yee (pp. 59-64) notes that in community-based care, there is often a disjunction between the formal care planning process, based on assessment and selection of service arrays, and what actually happens. "(The) clients and workers commonly negotiate the scheduling, priorities, and tasks to be accomplished. What workers actually do may diverge substantially from what they are formally assigned to do by their supervisor or person authorizing the service." Yee urges that care managers pay special attention to the interpersonal link between the client and the aide. She states that improved communication between decision-makers and aides is important, as well as better supervision of staff through support groups and in-service training.

Rosalie Kane (pp. 71-74) paints an ominous picture of home care if corrective steps are not taken to address both the responsibilities of the aides and responsibilities to the aides. While the aide is typically closest to the long term care consumer, with the most impact on "the consumer's efforts to live a life of dignity, meaning and authenticity," all too often the aide "is not given the latitude or the training" to see his or her work in this light. As Kane describes it, aides "often have at least one thing in common with their clients: perceived and actual lack of power." This situation is potentially dangerous, for it can breed mutual hostility and resentment, and lead to abuse.

SESSION RESULTS

INTERACTION WITH CONSUMERS AND THEIR FAMILIES

The first set of questions asked the aides to describe the most satisfying as well as the most difficult or challenging aspects of their jobs. It was evident from the direct answers and the nods of assent from those not speaking that all the aides thought the job was satisfying and personally rewarding. They clearly get positive feedback from both the clients and their families. Socialization with the consumers is important to the aides, and most said they feel like “part of the family.” Another source of satisfaction is an observed positive change in the client’s condition. Finally, aides (especially those with nursing home experience) gained special satisfaction by helping people stay in their own homes. Some of the comments:

“I like it when clients tell you they missed you if you haven’t been there, even if it was just one day away.”

“Satisfaction comes from seeing a big change.”

“Things you can do easily, they can’t do for themselves. You can help them do those things. That is very satisfying personally.”

“It is not just a job. You share your caring, your compassion. Things that are important to other people.”

“I get really attached to my patients. Listening to them, I know they repeat themselves, but I listen just like it was the first time. It makes them feel good.”

“Some of the people don’t eat what or as much as they should. But when you sit down to have a cup of coffee and talk with them, they will eat more. I would rather have them eat well than to have the bed made. The bed can wait”

“When I am working with my patients, I forget my own problems. We are helping each other. I gain a lot from that.”

“If you cheer up a depressed person, you give them something and they give you something back.”

“I like home care. It saddens me to see persons go to the nursing home. Even in the good ones (nursing homes) people don’t last long. The best we can do is keep people in their own homes. That is why I like my work.”

“Unlike the nursing home, where I used to work, we have time to listen to the people. In the nursing home, you can’t focus on one person, it’s rush, rush, rush.”

“I don’t think of it as my job. I think of it as going to visit my friend.”

“With this job, I feel I have a purpose in life.”

“Sometimes, I feel guilty for being paid, since this job is so personally rewarding. I say to myself, they actually pay me for this!”

As for the difficult aspects of the job, the aides expressed a sense of loss when the client’s needs grew to the point that home care was no longer appropriate.

“The most difficult situation is when you can’t help the person any more and they have to go to the nursing home.”

“The hardest thing is the personal attachment, when you can’t serve a family any more.”

“I can’t provide total care.”

One aide addressed the dilemmas of being a friend or a surrogate family member. She saw her main job as keeping the person out of the nursing home, but “it is hard to do this job if you can’t draw the line between being a friend or a family member. You can’t just play cards with the client every day. The person needs a bath (and other services).” In contrast with this view, most aides thought that being a friend was a positive factor, since it built trust between the aide and the person being served. That allowed the aide to maneuver even difficult clients into doing the things that were necessary, such as taking baths or eating properly.

There were several comments about the challenges posed by persons with dementia. Some aides had been falsely accused of taking things, and one situation even was referred to the sheriff’s department. A few aides admitted that their patience wore thin after a long period of serving a person with dementia: “When you are tired, you get frustrated with the constant repetition or the paranoia.” Most difficult, however, was the situation where the client no longer recognized the aide who had cared for him for a long time: “It is hard, very hard.” Another aide recounted the touching story of her client, who is in the advanced stages of dementia. She sleeps on a recliner in the living room, and her husband tries to sleep next to her on another recliner. Because the husband cannot get a good night’s rest, his health is deteriorating. The aide volunteered to stay over two nights a week (no one else would) in exchange for being assigned to only this one case. This way, the husband can get some rest.

Family involvement, or lack of it, can make the job difficult.

“Problems occur when families don’t understand the situation, how serious Mom’s condition is. Communication sometimes gets messed up.”

“You see families frustrated with the level of complexity of the care. They can’t do it all, but they don’t want you there, either. You have to talk with them and tell them you understand and want to help. But then there are other family situations where the family doesn’t even try to help.”

“Sometimes the family doesn’t appreciate your work. In one case, when I left, (the client’s) health left too. His daughter knew I was doing a good job, but not all the rest of the family understood.”

“I may hear complaints, but I have to think where I am coming from. You need to keep good communications, keep clear on the ground rules.”

(In response to a comment about critics of public spending for home care who argue that families should take care of their own) “When people criticize these programs, they don’t understand the programs. They haven’t been in the shoes of the family caregivers.”

One area of family involvement that drew several negative comments was the presence of other (sometimes several other) family members in the house who either were not supposed to be there or wanted services even though they were not part of the “case.” There were instances where people left dirty clothes and dishes for the “maid” to clean. There were also complaints that some family members could do a lot more for the “patient” than they do; instead, they expect the aide to wait on them.

“Sometimes, you find you are working for four or five people, but you are getting paid for just one.”

The more usual situation was not that family members were taking advantage of the aide, but were trying to do too much, or had needs of their own that could not be overlooked. For example, a spouse may be almost as frail as the client, and also needs help getting to the bathroom or in some other basic task. One aide described how she wound up washing and “perming” the hair of her client’s sister, because she was “jealous” of all the attention her sick sister got. A frequent observation was that families tried to do too much, rather than too little. Summing up the stress some families put themselves under, an aide said, “I can deal with the families who do too much. You just give them permission to ease back and let (the aide) do some of the care.”

Surprisingly, safety on the job was discussed in an off-hand way. There were references to guns and dogs in the house. One agency has a policy that all dogs are to be penned or kept in other rooms when the aide is in the house, and that all guns are to be kept in locked cabinets. One aide found a gun under the pillow when changing the bed, and reported to her agency that she would not go back until the gun was put away. Another found a machete under the mattress, and refused to return when she learned the person had some severe mental health problems. All aides reported cases of unwanted sexual advances, but many were very matter of fact about them, and did not feel particularly threatened. As some pointed out, however, all aides are very vulnerable, isolated in homes as they are. The strongest negative statements were:

“You never feel totally safe with men. You keep your antenna up.”

“One gentleman, I had to set him straight. But I don’t usually want to work for men.”

“Sometimes, when one of the couple isn’t being sexually satisfied, because the other is not healthy, they may turn to the aide. I have left a job because of these sexual advances.”

There was general agreement that men ask for lots of services, especially “intimate” ones, that they could do for themselves. Again, this was not usually seen as threatening.

The African American aides reported instances of racism, but appeared to be quite tolerant of it. Some did report leaving jobs where they felt uncomfortable, but others said it was something they “let roll off their back” and they went on with the job. They didn’t take it personally. They found some topic of mutual interest, such as sports or country music, and that got them past the uneasiness.

“Older people, you can overlook what they say. Younger people can be a problem, can be racist. You have to sit down and talk with them. An older person can’t hurt me.”

Aides often have to put up with verbal abuse.

“I was putting lotion on (Mrs. X’s) feet. I can’t tell you what she said to me, but after I stayed the required time, I left there in tears. She was yelling at me as I left.”

“One husband of a client was verbally abusive to all us aides. Some wouldn’t go back, but I couldn’t refuse to go there because I knew the woman needed my help.”

The last area of difficulty on the job is learning to balance many demands while still getting the job done. One aide worried about limits on program funding, since she thought people needed more, not less service. Others noted the conflicting directions from family members and the person being served. Some times there are unpleasant family dynamics, such as angry disputes, which disrupt the home and make carrying out tasks difficult. Those who served more than one person in a day or week found it hard to leave behind some of the issues or demands of the previous job. One aide noted it was a strain not being able to discuss cases at home, due to confidentiality, while her husband is free to blow off steam about his workplace. Finally, several aides said they simply did not have enough time to do all the things they were supposed to, and keep up with the socialization demands of the clients. Usually, the aides wind up staying longer than the allotted time: "I just couldn't leave until the job was done."

PREPARATION FOR, AND SUPPORT ON, THE JOB

Another set of questions probed the types of support the aides get on the job: training, supervision, and networking with co-workers. It was difficult to determine the amount and type of training the aides received. It appears that there is considerable variety in the formality and adequacy of training provided. One agency places its aides in nursing homes first, to see how they work out. Only then, do they place them in home settings. Other agencies require their staff to be certified as nursing home aides. Most aides said experience was the best teacher, but some aides seemed to downplay the need for training. Several repeated that "Mainly, you use common sense."

When pushed about the need for specific training on diseases or conditions, or methods of dealing with difficult circumstances, most aides recognized that "common sense" had its limitations. Also, there was some support for the idea of in-home training with a nurse showing the aide how to care for specific problems. Some said they get to see something once, and that is it. One aide complained, "You have to SEE the nurse in the home to learn," but her agency doesn't send out nurses very often. Only three or four agencies appear to offer regular in-service training, and at least two require staff to attend and pay staff for their time. There was some criticism that training tends to be via videos or lecture, not actual hands-on activities. Several aides at St. Joseph reported that they have been given information by their agencies, or by the client's family, on specific diseases or conditions, and then expected to read and learn on their own. One aide, who also has supervisory responsibilities, noted that many of the tasks done in the home by aides are considered skilled care in the nursing home. Instruction is done the first time by an R.N., but then there are times that one aide instructs another, who instructs another. She feared that important information might get lost in this process. Other comments:

“Our agency has in-services, keeps us updated. We have done training on lifting and using Hoyer's, Alzheimer's, Parkinson's, and so forth. (But) you learn just as much through experience, and by talking with supervisors.”

“A person's needs change a lot, so you need to get updated.”

“I worked in a nursing home for three years, and feel I am pretty well trained. I haven't come across anything yet I couldn't handle.”

(Commenting on the need to train young aides in interpersonal skills)
“Young girls don't know much about the life experiences and values of older folks. They need more than one week of training.”

When asked who controls the work in the home setting, most aides stated that no matter what was on the care plan, or what the formal control system was, the actual care delivered is a negotiated arrangement between the aide and the person receiving the care. Nonetheless, the aides said they had to learn to draw the line on improper or inappropriate activities, such as skipping services, falsifying timesheets, or buying a person cigarettes or liquor. As for the authority structure, some of the home care agencies have their own case managers, in addition to the AAA care managers, so the layers of authority can be confusing to aides and clients. Family members also try to define the aide's duties.

“The nurses from the agency give us a specific plan. But then you go out and the client says, 'Let's do this today, don't worry about the other stuff.' It is a negotiated thing between the aide and the client as to what really gets done.”

“The person's case worker decides; if a client wants a change, I have to get approval from my agency case manager.”

“I tell the gentleman I care for to speak with his case manager. I tell him to set his priorities and to let his case manager know what things would make it easier for him to stay at home.”

“I give the case manager input, based on what I see.”

“Basically, it is between me and the client. You have so many hours and you do what you can.”

“I do things in rotation; every other day I do things just for them as they want, like shopping.”

“Sometimes a family member wants a change, and I tell them to work through the process (with the case manager).”

“I had a lady with emphysema who smoked constantly and drank. She wanted me to buy her gin, but I wouldn’t. She said you aren’t doing your job because you don’t do what I ask. And I said, no, I am here to take care of you, and buying liquor is not taking care of you. If you want (liquor instead of care) then call the agency and get somebody else in here.”

Next, the aides were asked how they knew that they were doing a good job. Many proudly noted that families told them they were doing well, or put in special requests with the agency for them to continue or return to a case. Most also indicated they can judge from their own experience when they are doing a good job. More sporadic was the use of any kind of explicit evaluation by the hiring agencies. Several aides in the Escanaba session thought that UPCAP should let them know when they were doing a good job, but they had never heard this type of feedback.

“Our office uses an evaluation system. Also, the clients tell you, ‘You are doing just fine.’”

“You know yourself. You get what is important, done.”

“I try to think of the person as my mother or father, or think how I would like to be cared for. That is how I do my work. My clients give me a smile or a hug – that makes me feel I’m doing a good job. Sometimes they even write letters to the office.”

“I like it when they say thank you. Or when they tell your boss they want you on their case.”

“I had a client with amputations and deep bed sores, right to the bone. After a month of work, turning him every so often, we got these (sores) under control. That made me feel good, and I knew I did a good job.”

The aides were then asked how they were matched with clients. Very few reported anything like an interview with the prospective client. Most thought that the agency supervisors made assignments based on their knowledge of the aide’s experience and personality, and how that fits with the particular case. Some complained that while the supervisors may make good choices, many decisions get made by the schedulers, whose main obligation is to get the hours assigned, regardless of the appropriateness of the match between aide and client. There were other factors that came into play, as shown in the comments:

“We are just assigned; often, this is based on what geographical territory I work in. On occasion, some special cases are assigned to persons with particular experience or personality. Supervisors do this.”

“Our agency does an excellent job matching aides to clients, based on the aide’s experience.”

“My supervisor speaks with me and asks me if the case is something I can handle. Most assignments are negotiated this way.”

“Some are just assigned, but if problems come up, you move on.”

“I get a lot of my work through word of mouth referrals, from friends or neighbors of people I have cared for.”

“My agency takes into account your independence, flexibility and ability.”

Aides were next asked to describe the types of supervision they receive on the job. There were several arrangements evident, but many aides indicated that the supervision they receive goes beyond oversight to include support. There was some criticism of over-the-telephone supervision, since “I could tell them anything. They got to come to the home to see what I am doing and how the client is.” Most aides appear to get on-site supervision, at least some of the time.

“My agency does on-site supervision. Nurses also come on-site. We also get ‘supervision’ from the family and the client.”

“I don’t think I am being supervised, but maybe I am and don’t know it. I have been doing this for a long time and should know what I am doing.”

“I interact with the nurse and ask her if there is anything I should be doing.”

“I like it when the case worker comes out when I am there. Then I know she knows what I am doing and I can be sure I do it right.”

“Supervision depends on the aide, and their history with the agency.”

“On the first job, the boss says here it is, go do it. Call us if you have a problem. After, he follows up and asks, how did it go?”

“Our agency sends out new girls with an experienced aide to watch. The next day, the new aide does it and is watched by the experienced aide.” (Several comments, “That’s a good idea.”)

The next question probed into the types of interaction between and among aides. Many of the aides indicated that they don't see other aides much at all, nor did they think there was anything lost by not doing this. Most of the interaction is through notes left by one aide for the aide who handles the next shift, "So she knows what to do." Occasionally, aides overlap their shifts so they can discuss the needs of the person being served. Several agencies hold staff meetings and regular in-service training sessions, but not many allow for informal aide interaction. An aide from one agency noted that the agency is now so large that aides can no longer socialize at one aide's home, but "We still have fun things once in a while." Some aides suspected that the agencies were not eager for them to get together, since they might get "too organized." Some other remarks:

"I usually work on my own and don't attend any social events. I'm not a social person."

"We do charting. We may not meet, but we communicate that way."

"We don't get together, but it very well could be of benefit."

Most interesting was the reaction at the end of the session in Lansing, when the aides spontaneously began to interact, asking about various issues and practices. This group had been the least enthused about the idea of aide interaction. On the other hand, the Escanaba group was very supportive of the idea, and there was in fact a great deal of interaction during the focus group. These are indications, supported by the literature, that aides really need and benefit from interaction with each other.

The aides were asked about input by themselves and their clients in the care planning process. Many of the aides thought they did have meaningful involvement in care planning, but several indicated that they have to keep pushing and pushing to have their input taken seriously. Many aides thought the process for care plan development was too bureaucratic and slow moving. Several could not understand why two persons with very different needs received the same hours of care. There was evidence that many aides do not understand the process by which the types and amounts of services are determined. There were few comments on the role of consumers, although no one thought that the clients have too little input.

"I do have input into the care plan and I see the benefits from it."

"I think the clients have a lot of say, and they should."

"There are cases where the aide should be more involved, but the family has too much input. But you can still report any changes to the agency nurse, who arranges care."

“I ask the client, ‘What do you need, what would help you stay in your home?’ and encourage him to tell his case manager.”

The aides appear to see the AAA from two aspects, as the home base of the care managers, and as the overall provider of the waiver program. Only a few aides mentioned the role of the care managers.

“I seldom see the (TCOA) care managers. I hear from the clients that they had visited. Clients often get confused by all different people that visit them.”

“I have been there when the care manager did an evaluation. It is nice that they have regular visits, every ninety days to see how people like their care.”

“I feel the (TCOA) care managers are really good about knowing the cases and making service choices. I have lots of interaction with the care managers and they are really good about authorizing services right away. Also, the variety of services is great, especially respite.”

“The (Region IV) care managers don’t always get enough information for us, but that is often because the client or family doesn’t tell them the truth about who is in the home.”

“UPCAP should tell us we are doing a good job. We never hear that from them.”

“I have gotten compliments from (an UPCAP care manager).”

“UPCAP should provide hands-on training for aides.”

Some of the remarks related to the programmatic role of the AAA:

“TCOA makes it possible for people to get the extra care they otherwise wouldn’t be able to get. You have services in there every day, and that is important, since a lot can happen in 24 hours. The aide may be the only person visiting that client.”

“If not for (the waiver), we wouldn’t have jobs, and the clients wouldn’t be at home.”

PROSPECTS FOR HOME CARE CAREER

The last set of questions asked whether the aides intended to stay in this line of work, and what changes would make the job more attractive. All firmly stated they wanted to continue doing this type of work. One aide said she would like to

go to school to become a nurse, while another said she would continue only if she got enough hours to receive benefits (workers in her agency with less than 32 hours per week got no benefits). Other comments:

“The ones who can do this work should keep at it. It is rewarding work.”

“By helping others, I have helped myself.”

“I am definitely staying. I love this job.”

“This is the best job I ever had. I do wish there were more benefits, even for part-time people.”

As for improvements in the job environment, there was strong support for increased pay in the St. Joseph and Escanaba groups (and mention of it at Lansing). Several aides said that “preferred” or the most experienced aides should be paid more than beginning aides. This would be a good work incentive. Another suggested “hazard pay” when she agreed to travel in bad weather to cover for another aide who had “called out.”

Most thought that health insurance was a critical benefit that should be available to any full time worker. (There was also some discussion of whether 36 or 40 hours should be considered full time). Aides stressed the need to give workers enough hours to become full-time and thus eligible for benefits. There was also some discussion of the issues of risk and liability, especially when transporting clients in the aide’s car, or when taking a client outside in snow and ice. Several aides mentioned the need for a mileage allowance in addition to the situations where they transport the client to a covered service. Another aide even suggested that the agencies provide a company car. One aide said that a retirement plan would be a good idea, while another liked the opportunity for involvement in the inner workings of the office (she was involved in personal improvement team project). One aide who was a mother indicated that day care is a major issue: “My family suffers sometimes because I go to work instead of staying with the kids.” Only one aide seemed to see the virtues of specialization (“You get good at something.”), while most preferred variety in their work.

The St. Joseph group was very united on the need to improve the communications between the AAA, the home care agency and the aide, so that the aide goes into the home with the best information possible. They thought that often they found the condition of the client different from what they were led to expect, and there were often other factors, such as live-in family members, they did not expect. Another communication issue involved directions to the worksite: one aide recounted her difficulty in finding an apartment complex, and others indicated they had had similar experiences.

CONCLUSIONS AND RECOMMENDATIONS

One cannot be involved in a discussion of home care with aides like those involved in the three sessions described above, without being impressed by their dedication to service, their respect for diversity or their experiential wisdom. They are motivated by more than financial incentives, which is evident by the fact that hourly wages for aides are less than those paid by most fast food restaurants. In addition, very few of the aides have any fringe benefits (only 9 of the 28 reported they had health insurance). Despite the lack of adequate pay and benefits, all of the aides expressed a strong desire to continue in this line of work (one who loved her work questioned her ability to continue without benefits, given her family situation; another was a college student uncertain about her future). This does not mean that wages and benefits are unimportant to this group, since over two-thirds commented on their wage/benefit situation.

Weighing the findings of these sessions against the picture found in research, it appears that the situation is not as grim as one could be led to expect. Aides do not feel powerless or resentful. They still have the capacity to show caring compassion, and their patience and tolerance in the face of adversity is amazing. They do have wants and needs that should be attended to, however. There are even needs that some of them do not recognize that should be addressed.

Various parties can take steps to improve the likelihood that people will continue to join the home care aide ranks. Only the state can address the issue of rates paid in more than a marginal way. Of course, this issue is tied to rates paid to aides in nursing facilities, home health agencies and mental health group homes. Given the critical importance of aide services in long term care generally, there must be attention to the link between quality and what is paid for hourly wages. Since there is obviously a limit to what the state can pay (in both numbers of aides and hourly rates), there also must be some creative exploration of alternatives to one-on-one aide services. Assisted living is one avenue to explore, as is the use of technology to reduce or replace the role of the aide in some cases. One aide had a message for state policy makers:

“I would just like people in Lansing to know that there is a large portion of the population that is elderly or baby boomers. Somebody must do something. It is not just us (aides) saying we need a raise. This is not something for the future. They must do something now. There are so many people who need care, but some of us will be saying, ‘I cannot afford to keep doing this job that I love’.”

The AAAs can help improve the employment situation for aides by working with the home care agencies to elevate their standards of recruitment and training. Aides commented that AAAs could do a better job gathering information on the

clients and the home situation, so that when the aide visits the home for the first time, she is prepared as much as possible for what she will find there. Some aides were more critical of their own agencies than the AAAs on this score, saying that they did not always receive all the relevant information collected by the AAAs. Aides seemed to misunderstand the role of the AAA in training (it would not be appropriate for AAAs to train their contractors' aides) or in communicating directly with aides (the UPCAP group wanted to have the AAA tell them they were doing a good job). Another issue was that aides do not always understand the criteria used by the AAAs to assign types and amounts of service. They see people who, in their estimation, need more or less than what has been approved in the care plans. While they need a better grasp of this process, they also need to be more sensitive to the expressed wishes of the consumers of services. There seemed to be no awareness of "consumer-directed care" in the sessions. Both the waiver recipients and their aides could expand their horizons as to the possibilities of home care, and the AAAs can take the lead on this count.

The sessions revealed several areas where home care agencies need to do a better job. First, the recruitment process needs to be strengthened. Aides worry that there are not enough new aides entering the field. Marki Flannery, who runs a home care agency in New York City, says the best source of quality recruits is her own staff. They are given a bonus for every aide they recruit who successfully goes through training and stays on the job for a minimal period of time. (Comments made to a group of AAAs in Lansing, September 23, 1998). There should also be some basic screening criteria to weed out persons with criminal convictions and DUI driving offenses.

There is also considerable variation in the amount and quality of training for aides, as the aides report it. This should be an area of special concern. New aides should be given an adequate time to absorb the basic information required, and to demonstrate their learning in hands-on situations. During their first few visits to clients, new aides should be "mentored" by experienced aides or the aide supervisor. Regular in-service training should be held on a required basis, and aides should be paid for their time at these training sessions. The topics for the in-service training should include not only health and related topics, but also such areas as cultural awareness, interpersonal relations (including the stresses faced in the aide's own home). The in-service sessions also could provide another valuable opportunity to the aides, by giving them the chance to interact informally over lunch. It is evident most aides are isolated from one another, and they need to exchange information and offer moral support to one another. They need both unstructured and structured group interactions. This would be a significant boost to their morale, as well as a way to improve the quality of the services they render.

Home care agencies need to identify some simple, but effective, ways to communicate to their aides that the aides are valuable parts of the organization.

They need to get good information on the cases, clear and supportive supervision (on-site, not by telephone), and feedback about their job performance. Aides' suggestions about care for their clients need to be taken seriously, and reasons for acting or not acting on suggestions explained. An annual recognition luncheon or dinner would be a good way to get the staff together in a way that is virtually impossible on a daily basis. (Another Flannery suggestion). A more difficult-to-implement action would be the development of some financial incentives for quality performance (combination of longevity and reliability, for example). Given the reimbursement restrictions of the waiver program, this would be difficult to manage, but it is worth considering.

All these measures should help in the retention of aides. Finding quality people, training them well, and recognizing their contributions may appear to cost more than the current way of doing business. It is not as costly as constant turnover or as destructive as poor quality. Given the service motivation of aides like those in the focus group sessions, even some minor steps in the right direction will have positive payoff.

I recommend that the AAAs meet with the provider agencies in their service areas, to discuss ways to mutually address the issues and concerns raised by both this series of focus groups and the findings of the focus group sessions with waiver recipients and their family caregivers.

APPENDIX A: SAMPLE LETTER TO HOME CARE AGENCY

Dear (Agency Executive),

I am writing to ask for your assistance in improving the services in Project Choices. As one of the initial Home and Community-Based Waiver operators, the Tri-County Office on Aging (TCOA) successfully implemented Project Choices in 1992. In our effort to maintain and improve the quality of services provided, TCOA has secured the services of a consultant, Ronald Eggleston, to conduct focus group sessions with home care workers. Mr. Eggleston formerly worked in the Michigan Medicaid Program, where he was instrumental in developing the Home and Community-Based Waiver Program.

We would like to hear the opinions of home care workers such as those employed by your agency, since they deliver the majority of services provided under the waiver. These workers may have a unique perspective on the ways the Waiver Program operates at the delivery level: the interaction of caregiver and care recipient. Therefore, the sessions will explore the issues and challenges of providing care to persons who need long term care. Using the information gained from these sessions, TCOA will work with you to improve the quality of waiver services.

The sessions will be tape recorded, but we will not share these tapes with the employing agencies. We will, however, share the general findings and any concrete suggestions that emerge from these sessions.

We ask you to help us in the following way: Please provide us with a list of 6 to 10 persons who provide personal care and would be available for a two hour focus group discussion between 1:30 and 3:30 PM on March _____. Please provide a telephone number where we may contact each person. We will select, randomly, one or two persons from that list, along with persons from other agencies, to participate in the session. Persons attending will receive an honorarium of \$30 for participating in the session. The session will be held at the TCOA offices at 5303 South Cedar Street in Lansing.

To allow time for arranging the session, we ask you to respond by March _____. We appreciate your cooperation in helping to improve Project Choices.

APPENDIX B: HOME CARE WORKERS BASIC INFORMATION

1. Name _____
2. Your age _____ and sex M__F__
3. Your employer _____
4. How long have you worked for this employer? _____
5. How long have you been a home care provider? _____
6. Have you worked for other home care agencies? _____ If so, how many? ____
7. Have you worked in a nursing home or residential care facility? _____
8. In a typical week, how many persons do you provide home care for now?

9. Could you estimate how many persons you have served overall? _____
10. As a home care aide, do you receive any benefits, such as health insurance _____, retirement _____, or other (name it) _____?
11. Do you see yourself staying in home care _____ or going into some other type of work (such as _____)?

APPENDIX C: SCRIPT FOR HOME CARE WORKERS' FOCUS GROUPS

My name is Ron Eggleston and I have been hired by _____ to help improve the Home and Community-Based Services Waiver Program, variously known as _____. Since persons like yourselves provide most waiver services, _____ is very interested in your thoughts and feelings about your jobs.

I will ask you a set of questions and I want as many of you as possible to respond, briefly, to those questions. Please speak up and speak out, since we are recording this session. We will NOT let your employer hear this tape, so please be frank and honest with your comments. We want to hear anything positive or negative about your work situation that relates to the questions I will ask. We will use the information to compile a report that identifies key issues, positions and problems, so that _____ can work with its provider networks to improve _____.

This session should last less than two hours. At the end, you will be paid \$ 30 for your time in helping us understand the way the waiver program works “on the front line.”

I want to spell out a few ground rules for you, before we begin.

1. Everyone here has experience as a home care worker, so each of you has some valuable information to share. We will go around the table in order, to allow each of you to participate.
2. Every question I ask has a purpose, so please consider it seriously.
3. Allow everyone to participate by keeping your answers fairly brief, and please do not carry on side conversations that will be distracting.
4. You may agree or disagree with others, but please do not criticize others, because there are no “right” or “wrong” answers, just different viewpoints about the type of work you do.
5. When a response to a question occurs to you, just jot it down so you do not forget it while waiting for your turn to speak.
6. If you do not have a response to a question, say “pass” – I will try to check back with you before moving on to the next question, just in case something comes to mind.
7. Please fill out the paper that asks for basic information about you and your employment experience. Person-specific information will not be

shared with anyone, but all of the questionnaires will be used to create a general picture of the persons involved in the focus group sessions.

Now, let's go around the table and let each of you introduce yourself, indicating how many years you have been a homecare worker. Also, tell us one thing you would like us to know about you – a talent, an interest, a hobby, etc.

Let's now start with some questions about your work in the home with the person or persons you care for.

1. What are some of the most satisfying aspects of your job?

Prompts:

- Personal relationship with the person cared for?
- Sense of personal responsibility or pride in accomplishment that comes from helping those in need?
- Opportunity for personal growth?
- Opportunity for professional growth (knowledge based on experience)?

2. What are some of the most challenging or difficult aspects of your job?

Prompts:

- Hard, physically difficult work.
- Unpleasant tasks
- Boredom
- Transportation to job
- Unsafe neighborhood or building
- Lack of supplies or equipment
- Excessive demands by person cared for, or by family
- Person cared for is abusive or disoriented
- Nonregular work hours
- Scary to be left alone with dependent person?
- Working for a person who is dying
- Conflict between wishes of client and the family?
- Asked to do something wrong (such as buy alcohol)?

3. Who is in control of your work in the home? Who decides what work you do?

Prompts:

- You
- The person you care for
- You and the person “work it out”
- The family
- The company/agency you work for
- The Area Agency
- Who?

4. Do you ever get upset with the person you care for, or his/her family? Do you ever feel people expect too much of you, or that they don't appreciate what you do?

5. How do you know that you are doing a good job?

Prompts:

- Your own sense of accomplishment.
- The person you care for tells you.
- Your agency supervisor tells you.

Now I will ask some questions about the way your job fits into “the big picture” of the company you work for and the waiver program that pays for care.

6. Did you get enough training for the work you do? Would you like more training, and if so, in what areas?

Prompts:

- Patient management techniques
- Disease specific information
- Rehab procedures/techniques
- Nature of death and dying
- Working with families

7. How were you matched with the person you care for: were you just assigned or was there an interview process involving that person?

8. How much supervision do you get and is it enough?

Prompts:

- Is it in person, or over the phone?
- Is it onsite?
- Through the person you care for?
- By the family?

9. Do you have any interaction with other workers like yourself? Would you like to?
10. Do you have any input into the care planning process for the person you care for? Does anyone ask for your ideas and listen to them? Should you be more involved?
11. How much input does the client have into the care he/she is getting? Should there be more or less?
12. What role does _____ and the care manager have in your work? Do you think the care manager helps or hinders your work? Do you have any other opinions about _____?

Lastly, I have a few questions about the future of your work.

13. Do you think that you will continue to do this type of work, or not?
14. What changes would you suggest that would make your job a better employment situation?

Prompts:

- More pay
- Fringe benefits (health care, retirement plan)
- More support or training
- More control over the job
- More input into care planning
- Opportunities to specialize
- Opportunities for advancement, including supervision
- Educational opportunities

15. What one change would make your job better?

Thank you for your time and participation. Your thoughts and opinions will be used to improve _____.

