



HOME CARE AIDE ASSOCIATION OF AMERICA

THE HOME CARE AIDE ASSOCIATION OF AMERICA IS AN AFFILIATE OF THE NATIONAL ASSOCIATION FOR HOME CARE, LOCATED AT 228 7TH STREET, SE, WASHINGTON, DC 20003-4306.

Guiding Principles Governing the Delivery of Long-term Care

The Home Care Aide Association of America (HCAAA) believes that families and individuals should receive the long-term care that most effectively meets their needs, regardless of who provides the care or what model of care is used. No one model of long-term care service is appropriate and effective for every person or family. Long-term care may be provided in institutions, or it may be provided by families, agencies, or independent providers who are individually employed by consumers. For many years the payor chose the model that was most convenient for the payor, not the model most responsive to the consumer's or the family's needs. HCAAA recognizes the right of consumers to choose the type of care that best suits their needs, whether it is a single model or a mixture of models; for example, an agency provider in the morning, a family member during the day, and an independent provider at night. Any home care program provided with state or federal funds must be designed to meet the needs of the consumer rather than focusing on the model of delivery. At the same time, the program must provide accountability for the public funds expended.

The goal of home care is to foster independence in the least restrictive environment while safely meeting the consumer's needs. The consumer may be a family with a child with disabilities, a severely

mentally retarded individual, an adult with a disability, or a frail, at-risk elderly person. The consumer may be deficient in one activity of daily living (ADL), one instrumental activity of daily living (IADL), or in many ADLs/IADLs. The goal is to have the consumer participate in the planning and management of his or her care. The degree of planning and management varies according to the competence and interest of consumers and their families as well as the requirements of the payor. Home care in general and personal

care in particular are intensely personal activities, as they take place in the consumer's own place of residence and, in many instances, involve personal needs of the consumer such as toileting and bathing.

However, HCAAA is very aware that home care affects the consumer and the caregiver. Both the consumer and the caregiver have rights. Any publicly funded long-term care plan must recognize the rights of the consumer and the caregiver.

Basic standards of care must be

The National Association for Home Care (NAHC) established the Home Care Aide Association of America (HCAAA) in 1990 to provide a forum for the discussion of issues related to the work of paraprofessionals in home care. The majority of long-term care currently is provided by paraprofessional workers. HCAAA has closely examined the myriad complex issues involved in the delivery of long-term care. Recent years have seen an increased interest among people with disabilities in self-directed care. This trend has been accompanied by an increase in the use of independent providers—or consumer-directed personal care attendants who are hired and supervised by the consumer. A number of state-funded long-term care programs rely heavily on personal care provided by independent providers, primarily as a cost-saving measure.

HCAAA believes that individuals who are capable of doing so and choose to do so should be permitted to self-direct care. However, the organization is concerned by the lack of training, testing, and other quality standards in these programs. HCAAA believes the quality standards to which agencies are held should apply to all caregivers. Far from being a market protection issue, basic standards of care must be met to ensure minimum levels of safety for the consumer, the caregiver, and the community.

This white paper sets forth the rationale for HCAAA's position with a concise listing of the principles HCAAA believes should govern the delivery of long-term care—regardless of consumer, provider, or payor.

met to ensure minimum levels of safety for the consumer, the caregiver, and the community. This is balanced by the right of consumers to manage their own care. The industry needs a clear line of accountability for the quality and consistency of care provided under the program. The industry must also establish responsibility for adherence to program rules and applicable laws to provide accountability to the payor.

The consumers of long-term care services cover all age ranges and all levels of functional abilities; therefore, one profile is not appropriate. The three major groupings of individuals and their families needing long-term care services are (1) individuals with physical limitations; (2) the frail, weak, and elderly, usually with chronic illnesses; and (3) individuals with mental disabilities frequently accompanied by chronic illnesses and/or physical disabilities. There are many combinations within these groupings; no one model of long-term care service delivery, however, will meet the needs of each group or each individual.

The models of care delivery range from self-directed care to total managed care. The primary factors in determining the model of care delivery are twofold: the effectiveness in meeting the needs of the individual, and the preference of the individual in concert with his or her ability to manage the model selected. In many cases no one model will be most effective for the individual. HCAA supports any delivery model or any combination of appropriate models that maintain the consumer's highest quality of life possible and retain the maximum personal control in a safe environment.

Although consumers of home care services have rights and needs, so do the workers in long-term care. Whether the caregiver is an independent provider or the employee of an

agency or whether the caregiver is being paid from consumer's funds, from funds given to the consumer by a third party to purchase care, from the funds of an agency, or from the funds of any third party, the caregiver is entitled to have FICA withheld and paid, to have workers' compensation paid, and to have appropriate local, state, and federal taxes withheld and paid. The caregiver has the right to receive the protection mandated under all applicable federal health, safety, wage, and hour laws including the Occupational Safety and Health Administration. The caregiver has the right to be competently supervised and evaluated so that he or she can more effectively perform the assigned tasks.

The caregiver has the right to be adequately trained. The performance of certain tasks such as lifting can have a serious physical impact on both the consumer and the caregiver. Certain minimal acceptable ranges of safety must be established regardless of the payment source.

The caregiver has the right not to be exploited by the consumer, by the consumer's family and friends, by the employing agency, or by the payor, whether government or not.

The philosophical foundation on which the guiding principles of this position paper are based represents the fundamental elements of safety, protection, and fairness that should be in place no matter what model of long-term care service delivery is used.

Guiding Principles

- Care should foster maximum independence in the least restrictive environment. Caregivers should help consumers maintain optimal health status and emotional well-being.

- A home care program should ensure prompt, adequate, continuous services to eligible individuals regardless of delivery system. The standards applied in determining eligibility for services should be objec-

tive and stated publicly. The program should not exclude persons on the basis of age, income, type of impairment, residential setting, or arbitrary criteria.

- Consumers should be reassessed periodically to monitor continued eligibility and service needs. Utilization review must be defined primarily to ensure that consumer needs are being met.

- A grievance process should be established to provide a formal mechanism through which consumers and caregivers can report dissatisfaction and concerns about quality of care.

- A program should allow consumers to make responsible choices. Consumers should have the right to self-direct their care or choose agency administration without penalty in quality or quantity of care. Consumers should be permitted to receive services through a combination of service delivery modes.

- A program must comply with applicable state and federal labor health and safety laws and regulations.

- The care environment should be safe for caregivers and consumers: free of fear of abuse, neglect, exploitation, or inappropriate care.

- The state should be responsible for ensuring the competency of caregivers.

- A program should be adequately funded, and the funder should provide program oversight, set standards, and require accountability.

- A program should require a written bill of rights that advises consumers of their rights and obligations. Rights should cover such areas as dignity and respect, decisionmaking, privacy, quality of care, finances, and consumer responsibility. A program should clearly specify the role, rights, and responsibilities of all parties involved in the caregiving process, including the consumer, caregiver, agency, and payor.