Preventing Elder Abuse

by In-Home Helpers

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Introduction

An estimated seventeen percent of Americans over the age of sixty-five need regular assistance with their daily activities. Although families and friends provide much of this help, many older Americans rely on hired helpers to provide personal assistance (sometimes referred to as "personal assistance services," or PAS). The terms used to describe helpers vary widely and include personal care assistants, attendants, chore workers, in-home support service workers, and homemakers.

The intimate, prolonged and often unsupervised contact that helpers have with extremely vulnerable individuals has increasingly highlighted the need for safeguards to protect elderly clients. This concern is heightened by the fact that the demand for helpers exceeds the supply in many communities. The rising tide of support for "consumer-driven" approaches to providing home care services, in which individual consumers assume responsibility for identifying, screening and monitoring helpers, as opposed to licensed agencies assuming these functions, has further contributed to this concern.

This manual describes how in-home personal assistance services are organized, emerging trends and what is currently known about abuse by helpers. It further describes the benefits and limitations of safeguards that are currently in use and highlights initiatives that hold promise for ensuring greater protection to elders who need assistance. It is designed for agencies and individuals that have an interest in ensuring that adults with disabilities have access to safe and dependable personal assistance services in their homes.

Part 1 provides an overview of in-home helpers, including descriptions of the two primary models for delivering personal assistance services, the consumer-driven model and the professionally-driven model. It describes research and demonstration projects aimed at evaluating the benefits and risks of each approach, and the dearth of data that is available on abuse by in-home helpers.

Part 2 describes approaches and techniques used to reduce the risk of abuse by in-home helpers including screening, training, protocols, guidelines, codes of ethics and initiatives aimed at expanding the workforce of helpers.

Part 3 describes best practices, models and resources. It further describes national organizations that are addressing the needs of elderly consumers of personal assistance services and expanding the pool of qualified helpers.

Part 1: An Overview of In-Home Helpers

What are In-Home Helpers?

People with chronic illnesses or disabilities may need help with such basic tasks as eating, dressing, bathing, using the toilet, walking, shopping, preparing meals and doing laundry. This type of care is often referred to as personal assistance services (PAS); terms that are commonly used to describe paid employees who provide PAS include home health aides, personal care aides, personal care attendants, homemakers, in-home support service workers, and personal assistants. These various terms are used by different home care providers and funding programs. For example, paraprofessionals funded under Medicare are referred to as home health aides while persons carrying out similar tasks under Title XX programs are referred to as homemakers. Because there is considerable overlap and disagreement with regard to definitions, the generic term "in-home helpers" is used in this publication.

In-home personal assistance services may be paid for by the person receiving the help, family members, private insurance or state or federal entitlement programs. The federal government finances home care services through Medicare, Medicaid, Veterans' Administration programs, Older Americans Act funds, the Social Services Block Grant Program (Title XX) and various demonstration and waiver programs. The largest programs are Medicare and Medicaid.

Consumer versus Professionally-Driven Models of Care

As a major provider of in-home personal assistance services, the government has a vital interest in how these services are administered. There are two primary models for providing publicly funded services, the professionally-driven model (sometimes referred to as the professional management model) and the consumer-driven model. The two models vary in the extent to which they permit consumers, which may be the persons actually receiving care, family members or guardians, to control the hiring and supervision of workers.

In the "professional management model," workers are employed by public or private, non-profit or proprietary organizations including home care agencies, social service agencies, agencies that provide PAS exclusively, and others. These agencies, which are regulated by state licensing laws, assume responsibility for recruiting, screening, training, paying and supervising the workers. Payment rates are negotiated with the

public funding program and include the administrative costs associated with recruitment, training, supervision and payroll functions. Case managers assess clients' needs, develop care plans to meet those needs and assign workers to clients. In fully developed, professionally-driven programs, clients do not have direct control over the type of services provided, the choice of worker, or the work schedule although they may be given choices.

In the "consumer-driven model," clients receive funds or vouchers for purchasing their own help. This model is based on the principle that individuals with disabilities (or their chosen advocates) should have the primary responsibility for making decisions regarding the help they receive. Fully developed consumer-driven models place virtually no restrictions on clients regarding their hiring decisions. Clients may find helpers on their own through newspaper want ads, personal contacts or referral services. Some publicly funded programs permit consumers to hire members of their own families. Under the consumer-driven model, it is up to the consumer to negotiate pay and hours, calculate helpers' taxes, prepare filings, find replacements when helpers get sick, and resolve problems that arise. Helpers who work directly for consumers are typically called "independent providers." Most communities have registries that help consumers find independent providers; this service may be provided at no cost or for a fee.

Although public programs typically favor one of the two models, most employ elements of both (USGAO, 1999). As many as six primary types of "intermediary organizations" have been identified (Flanagan and Green, 1997), which vary in the level of fiscal and non-fiscal support they provide to consumers and, in the case of consumer-driven programs, whether or not they have restrictions against hiring family members.

There has been considerable debate over the benefits and limitations of the two models. Supporters of the professionally-driven model point out that it offers greater protection to consumers because workers are more likely to be screened, monitored and trained. They further argue that people with cognitive impairments cannot realistically participate in daily decision-making about their care needs, and that many elders lack surrogate decision-makers who can act in their behalf. Even when family decision-makers are available, critics question these decision makers' ability to truly represent elder family members' preferences. Of perhaps greater concern is whether impaired and frail individuals can defend themselves against unscrupulous, troubled or incompetent workers.

Proponents of the consumer-driven model point to the enhanced client autonomy that the model offers and the savings that result from eliminating administrative costs associated with agency services. They further point out that most elders can be instructed in carrying out employer responsibilities.

Historically, younger adults with physical disabilities and their advocates have favored the consumer-driven model while programs for the elderly have relied on professionally-driven approaches to providing care (Ansello and Eustis, 1992). This dichotomy has broken down in recent years, however, with advocates for the elderly increasingly demonstrating support for the consumer-driven model. Such prominent organizations as The National Council on Aging, the American Society on Aging, and AARP have explored consumer-directed programs for the elderly (Squillace and Velgouse, 1999; Stone, 2000; Coleman, 2001).

Olmstead Decision Fuels Consumer Choice

To some extent, heightened interest in the consumer-driven model may be attributed to a 1999 Supreme Court decision involving two women from Georgia who were living in state-run institutions despite the fact that professionals had determined that they could be appropriately served in community settings. The two plaintiffs charged that continued institutionalization was a violation of their rights under the Americans with Disabilities Act (ADA). Under the ADA, states are required to make reasonable modifications in policies, practices and procedures to

the extent that they do not fundamentally alter the nature of the service, program or activity. The Supreme Court's ruling affirmed that unjustified isolation constituted discrimination and that people with disabilities should not have to live in institutions or nursing homes if they can live in the community with reasonable support.

The ruling was followed by an Executive Order and a directive by the U.S. Department of Health and Human Services (DHHS) for states to increase their efforts to enable people with disabilities to live in the community and to improve access to cost-effective, community-based services. DHHS provided guidance to state Medicaid directors in how to transition qualified individuals into community-based settings and directed states to provide consumers with more opportunities to exercise informed choice.

In response, the federal government, aging and disability advocacy organizations, the Robert Wood Johnson Foundation (RWJF), and others have launched research, demonstration and technical assistance projects aimed at promoting consumer choice and evaluating its impact:

- Independent Choices: Enhancing Consumer Direction for People with Disabilities. This project, carried out by the National Association of State Units on Aging, involved the development of a tool for state policymakers and consumers to assess how consumer-directed their home and community-based services systems are and to assist them in making improvements. NASUA further launched nine demonstration projects and four research studies to assess the effectiveness of consumer-directed options.

- The National Council on the Aging and the World Institute on Disability jointly operate the National Institute on Consumer-Directed Long-Term Care, which provides education, training and research aimed at enhancing consumer choice.

- The Blue Ribbon Panel to Study National Policies for Personal Assistance Services, sponsored by RWJF and carried out by the Institute for Rehabilitation and Research, is a panel of experts assembled to promote consumer direction.

- The Cash and Counseling Demonstration and Evaluation Project, also funded by RWJF in collaboration with DHHS, is testing the effects of "cashing out" Medicaid-funded personal assistance services for the elderly and disabled. Consumers receive a monthly cash payment in an amount roughly equal to the cash value of the services they would have received under the traditional program. Clients can use their payment to hire their own workers (including relatives or friends), or purchase disability-related services and/or assistive technologies. Counselors are available to help with training, guidance and bookkeeping.

Research/Demonstrations Shed Light on Models of Care

The government has also sponsored several studies to evaluate PAS delivery systems and compare the two primary models for delivering them. Although it is too early to draw conclusions, a few studies have begun to yield preliminary findings.

Studies of consumer satisfaction with the two models suggest that seniors generally prefer help from agencies in managing their care. However, most are willing to assume responsibility for certain tasks including the hiring, scheduling and supervising of workers (Eustis and Fisher, 1992; Glickman, 1999). Those who are willing to participate in managing their own care tend to be individuals who have the most experience doing so and who have been doing it the longest. The type of assistance most seniors want help with is handling payroll functions and taxes.

Seniors enrolled in the consumer-driven model have identified several elements in particular that they favor, including having the option to allow family members to provide care. Preliminary findings of the

"Cash and Counseling" program have revealed that most clients use their allocation to hire in-home helpers and that most elect to hire family members and friends. In one of the program's demonstration sites (Arkansas), seventy-eight percent of the clients who hired helpers hired members of their families and fifteen percent hired friends, neighbors or church members. At a site in New Jersey, four-fifths of the clients who used their cash grants to hire caregivers hired members of their families and close to two-fifths hired friends, neighbors or church members (many hired more than one caregiver).

A study aimed at assessing program officials' perceptions of the two models revealed wide variations in how they viewed consumers' desire and ability to exercise choice (Tilly and Wiener, 2001). When asked whether they felt that seniors wanted to direct their own care, three administrators stated that older people preferred consumer-directed care, two said that older people preferred agency services, and three did not believe that older people preferred one model over the other. Similarly, when asked if they felt that seniors were as capable of directing their own care as younger consumers, the administrators were also divided: five felt that age was not a factor, and three felt that older people were less capable of managing their care or that they found it burdensome. When asked to list the advantages of the consumer-driven model, they ranked increased choice and autonomy, improved quality of life, improved satisfaction, greater flexibility and cost savings as the most important.

Rising Concern About Abuse

In 1996 and 1999, The National Council on Aging surveyed state administrators about the advantages and disadvantages of consumer-directed models (Lagoyda et al, 1999; Squillace and Velgouse, 2001). While the administrators cited many advantages, including increased consumer satisfaction and cost savings, the majority also expressed concern about the lack of quality assurance and the possibility of fraud and abuse. When specifically asked about potential legal and ethical concerns, 78% responded that they were concerned about abuse or exploitation of the consumer, 73% were concerned about fraud or misuse of funds by either the consumer or provider, and 70% had concerns about quality assurance.

Perhaps one source of professionals' concern about abuse can be traced to heightened awareness that many in-home helpers have criminal histories and that the proportion of workers with criminal histories appears to be on the rise. A 1988 study of workers in California's In-Home Support Services program (USGAO, 1996), for example, revealed that 6.4% of workers had criminal histories. In a follow-up project conducted in one California county, prospective new employees were fingerprinted and checked over a two-year period. Of the 462 prospective providers who completed the process, 10.7% had criminal records. In the following year, an additional 162 completed the process and, of these, 15.4% had prior criminal records.

In Texas, where persons with certain convictions are barred from employment in long-term care and home health care settings, the facilities are provided with reports of all potential employees' convictions. In 1995, facilities received reports on 3.4% of the potential employees. In 2000, that percentage had risen to 9.1% (Bermea, 2001).

This growing concern about workers with criminal pasts has led states to implement laws barring persons with certain convictions from employment. However, owing to the shortage of workers, which is attributed to the low pay workers typically earn and the lack of opportunities for advancement, many agencies

and individuals feel they have no choice but to hire workers with criminal histories. The extent to which agencies and individuals have access to information about potential employees' criminal histories, as well as statutory parameters and guidance with respect to what crimes should disqualify workers from employment and for how long, vary widely from state to state.

The issue of criminal background checks is mired in controversy. When New Jersey passed legislation requiring all home care workers to have FBI fingerprint checks, four hundred current employees, some of whom had been working for years, were found to have committed disqualifying crimes (Layton, M.J., 2001). Challenges to these laws are also foreseeable as evidenced by recent challenges to policies barring people with certain convictions from employment in nursing homes. After Pennsylvania prohibited facilities from hiring people with certain criminal convictions, the law was declared unconstitutional (Cook-Daniels, L, 2001). In some communities, disqualified workers have been successful in getting hiring decisions overturned by convincingly arguing that committing one type of crime (or crimes against younger people) did not increase the likelihood that they would commit crimes against elders.

Findings on Abuse by In-Home Helpers

Despite the mounting concern about abuse by in-home helpers, little research on the subject has emerged from either the fields of elder abuse or consumer choice. One of the few large-scale studies that examined abuse by helpers was sponsored by DHHS and conducted by the University of California, Los Angeles (Doty, Benjamin, Matthias, & Franke, 1999). The study compares the consumer-driven and professionally-driven models along multiple criteria, one of which is reported incidents of abuse. The study focused on California's In Home Support Services program, which provides services under both models.

The study revealed relatively low levels of abuse in general, and no significant differences between the two models with respect to clients' safety and unmet needs. A full 97% of the clients in professionally-driven models, and 98% of clients in consumer-driven models, reported that they had never been pushed, shoved or physically hurt by their attendants. Where differences were noted between the two groups was with respect to financial abuse and neglect; clients in consumer-driven programs reported fewer concerns in this area. When asked whether they had ever thought that their provider was responsible for money or other items disappearing from their homes, 93.5% of the clients in consumer-driven models reported no concerns compared to 89.1% of the respondents who received professionally-managed care. When asked about neglect, 83.6% of clients of consumer-driven care models reported "never" having been neglected by their providers, compared to 71.7% of clients with professionally managed care. A full 95% of the consumers in both models reported that their provider had "never" threatened them.

The researchers also attempted to test the assumption that the risk of abuse and neglect is higher in consumer-driven programs when family members are paid to provide care. They concluded that this was not the case. Clients with family member providers, in fact, reported fewer instances of abuse and neglect than clients with non-family providers.

Part 2: Ensuring Consumer Protection

A variety of approaches are currently being used or developed to reduce the risk of abuse by in-home helpers. Several of these strategies involve the screening and tracking of known offenders and ensuring that they are not provided with opportunities to re-offend. The success of this approach depends, however, on the systems' capacity to monitor and document incidents that occur in a largely unsupervised environment. Other approaches focus on building the workforce of qualified helpers to ensure that clients have an adequate supply of helpers from which to choose, providing qualified workers with the skills and information they need to perform their jobs, and clarifying expectations about what is and what is not appropriate behavior. Approaches that are currently being used are described in this section.

Regulation of Federally Funded Programs

The federal government exercises some oversight of in-home helpers through regulations and requirements for participation in federal programs. For example, under the Medicare and Medicaid Patient and Program Protection Act of 1987, "any individual or entity convicted of program-related crimes or who has been convicted under federal or state law of a criminal offense related to neglect or abuse of patients in connection with delivery of a health care item or service" are excluded from participating in Medicare, Medicaid and Social Services Block Grants programs.

State and Local Licensure and Registration

The extent to which states regulate in-home care programs and workers varies widely across the country (USGAO, 1996). While some states require licensure for all types of home care providers, most only license or regulate certain types of organizations or professionals, and few have requirements for the most common categories of home care workers, including in-home helpers. Some states prevent non-licensed or non-registered providers from advertising.

Screening

Simple screening techniques that are commonly used by agencies and programs to assess candidates' suitability for employment and eliminate unskilled or unscrupulous candidates include written applications, personal interviews and the checking of references that applicants supply. Supplemental steps may include background checks of criminal records

kept by local, state and federal law enforcement agencies (see next section). Employers may also check child and dependent adult abuse registries, motor vehicle records, sex offender registries and professional disciplinary board records. Infrequently used practices include alcohol and drug testing, psychological testing and background checks to determine whether applicants have histories of psychiatric problems or mental illness.

A variety of impediments to these forms or screening have been identified including widespread reluctance on the part of past employers to incur liability by providing candid appraisals of former employees. Many provide little more than verification that a worker was actually employed by their agency and workers' dates of employment. The fees attached to background checks have also been cited as an obstacle for many agencies and individuals.

Criminal Background Checks

Criminal records, which typically include police arrest reports, prosecution data, court determinations and records from corrections departments, are kept by both state and federal law enforcement agencies. The Federal Bureau of Investigation (FBI) collects information from all states and can provide information to local and state agencies about crimes committed outside their states.

Both federal and state laws dictate who can and who must conduct background checks and the categories of workers that are covered. As noted earlier, Medicare requirements for home health agencies require criminal checks for employees of home health agencies. In addition, the National Child Protection Act of 1993, which provides for criminal background checks of persons who work with children, was amended in 1994 to also cover persons who provide care to the elderly or persons with disabilities. The act does not permit or require national checks; this authority rests with states. However, the federal legislation paves the way for states to develop screening legislation and encourages them to do so.

More than half the states authorize national criminal history checks for certain categories of people who work with children, the elderly or individuals with disabilities. State laws typically protect hiring agencies against liability for civil damages resulting from decisions to employ, refuse to employ or discharge employees as long as they are acting in good faith. The statutes can be found in state licensing laws, laws governing state social welfare agencies, and laws covering specific information systems such as criminal record repositories or child or elder abuse registries.

Despite these statutes, a 1996 survey by the General Accounting Office (USGAO, 1996) found that persons providing in-home services under consumer-directed service programs are not typically subject to criminal background checks. In addition, while states with statutes requiring background checks may access FBI data, few states do so for home care workers.

Because the information systems used for criminal background checks were created for other purposes, they do not provide guidance to prospective employers in how to use the information in making hiring decisions. States vary in the extent to which they provide guidance to employers. Some offer no guidance, while others specify that certain crimes should bar employment. Typically, disqualifying convictions include "crimes against persons," sexual crimes and crimes having to do with families. Certain convictions permanently disqualify applicants from employment while others prevent them from working for specified periods of time (typically five years or ten years). Some state laws give hiring agencies discretion in hiring decisions but direct them to consider mitigating circumstances,

such as an employee's age at the time he committed a crime or the length of time elapsed since the crime, in making hiring decisions.

This lack of guidance in using criminal background information has been problematic for some agencies that hire in-home helpers. In addition to concerns about their liability in hiring persons convicted of crimes, agencies have further expressed concern about the lack of guidance in evaluating arrests that did not result in convictions, or expungements. The fees associated with background checks have also been cited as a barrier.

Registries of Abusers

Registries are databases of abusers that contain documented findings (convictions and substantiated reports to APS or other investigative agencies) of client abuse, mistreatment, neglect or misappropriation of clients' property. Most also contain workers' statements disputing negative findings. Information contained in registries is typically made available to individuals or agencies that employ helpers. A few statewide APS programs have established registries of substantiated abusers that include information on paid caregivers as well as reports of abuse by family members, acquaintances and others. Although all states maintain registries of some nursing home workers noting those who have been involved in incidents of abuse, neglect or misappropriation from patients, only about one-quarter of the facilities have incorporated home care workers into these registries or developed separate registries for home-care workers.

Registries vary with respect to the standards or criteria they use, due process protections for alleged perpetrators, who has access to the information, who operates them, and how the information can be used. Because persons listed on registries have not necessarily been convicted of crimes, placement on a registry is based on a lower standard of proof than that which is used in criminal background databases.

Training

Several communities (and the National Center on Elder Abuse) have developed training materials aimed at reducing the risk of abuse and neglect by in-home helpers. Training to workers is believed to reduce the risk of abuse in a number of ways. Certain behaviors by care receivers, including combativeness and aggression, have been found to be associated with abuse in nursing homes (Pillemer & Moore, 1990; Goodridge et al, 1996), suggesting the need for training that provides workers with insight, skills and information to cope with and manage these behaviors. Training that instructs workers in their reporting responsibilities can clarify expectations with respect to their conduct toward clients and alert them to the penalties for abuse.

Codes of Ethics

The sustained and often intimate contact engendered by the caregiving relationship may, in some cases, lead to a blurring of the boundaries between personal and professional conduct. Accepted standards of confidentiality and privacy may be breached, and clients who develop close relationships with their helpers may wish to give them gifts, help them with personal problems, loan them money or become romantically or sexually involved. Clients who suffer from cognitive impairments may tolerate or initiate inappropriate behavior. Persons who rely on others for their basic necessities are further susceptible to undue influence, exploitation and subtle forms of coercion. Some agencies have found it helpful to develop codes of ethics and/or policies to clarify appropriate conduct with respect to client (and worker) privacy, confidentiality, gifts and personal or sexual relations between workers and clients.

Consumer Education for Families

Several organizations have developed materials aimed at reducing the risk of abuse by providing seniors and family members with instruction in how to find, screen and monitor in-home helpers. Some have published "tips" to reduce the risk of abuse,

including such measures as securing elders' valuables, requiring receipts for purchases made by helpers, employing more than one worker (with alternating shifts), closely monitoring bank accounts and phone bills, and keeping important financial information and documents locked up. Some encourage family members to make unannounced visits.

Quality Jobs/Quality Care Approaches

Another promising approach to ensuring quality care and reducing the risk of abuse has emerged from home care advocacy organizations. These groups have recognized the importance of expanding the pool of qualified, trustworthy workers as a protection for both consumers and workers.

The current critical shortage of workers that exists in some communities can, to a great extent, be attributed to the low pay workers earn and the lack of opportunities for advancement. Owing to the unsupervised nature of the work (particularly in the case of independent providers), workers also lack basic protections that are afforded other workers, including guarantees against harassment, discrimination and workplace hazards. For these reasons, the field attracts individuals with limited employment options, including immigrants with limited language or literacy skills, persons with criminal histories, and people with little education or training. To remedy this situation, worker advocacy groups are attempting to raise wages and improve working conditions. Some are further providing guidance to communities in effective approaches to recruitment. These include working with unions or programs for displaced workers and persons who are returning to the workforce after extended absences.

Uniform Standards for Training and Supervision

Some advocates believe that the first step toward achieving greater accountability by care providers is to achieve greater uniformity; formal safeguards currently vary widely across political jurisdictions, public programs and categories of providers. The Home Care Aide Association of America (HCAAA), for example, is attempting to achieve greater uniformity in titles by proposing the use of the generic title "home care aide," for all paraprofessional workers, regardless of the setting in which they work (including employees in long term care facilities). The organization further proposes the use of three sub-categories that reflect workers' training and experience. For example, under the proposed classification system, a home care aide I would assist with "environmental services," such as housekeeping, shopping, laundry and errands, while a home care aide II would be approved to assist with non-medical personal care, including such tasks as bathing and dressing. The rationale behind this approach is that a universal classification system would facilitate the acceptance of quality assurance systems. Rather than "reinventing the wheel," administrators could extend existing quality assurance and screening programs to cover comparable workers. Greater uniformity in categories would further allow individuals to work their way up a career ladder or path, which, in turn, would enhance job satisfaction.

Conclusion

The fact that in-home personal assistance is provided to extremely vulnerable people in a largely unsupervised setting has raised concerns within the elder abuse prevention community about the potential for abuse, neglect and exploitation. This concern is further heightened by growing support for consumer-driven models for providing PAS, an approach that reduces professional involvement in the hiring, screening and monitoring of in-home helpers. This change is occurring at a time when the labor work force of in-home helpers is largely unregulated and insufficient to meet the demand in many communities. As a result, persons who have limited employment options, including workers with criminal histories, are increasingly seeking employment as in-home helpers, further raising the specter of abuse.

The spate of research and demonstration projects currently in progress have focused, to a great extent, on consumer satisfaction with the models and their financial impact. Surprisingly little attention has been paid to the potential hazards that the consumer-directed model poses with respect to abuse and neglect. Neither do these studies reflect current knowledge about elder abuse, which could help to identify high-risk situations and suggest measures to offer greater protection. For example, preliminary research findings have demonstrated that consumers generally favor hiring members of their own families to provide their care, and that they are generally satisfied with the care they receive. These studies have, however, failed to distinguish care that is provided by loving partners and spouses from that which is provided by troubled adult offspring who have assumed caregiving responsibilities because they lack other employment opportunities. Neither have they explored the risk of abuse by family caregivers in families in which there has been a history of domestic violence. The methodologies have further failed to explore forms of abuse that are likely to go unrecognized by impaired consumers, including undue influence or abuse to persons with cognitive impairments.

As the debate over consumer direction continues, there is clearly a critical need for professionals in the fields of elder abuse prevention and adult protective services to participate. Failure to recognize the risks and develop appropriate safeguards will render an extremely vulnerable population even more vulnerable.

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Part 3: Best Practices and Resources

Attorney General's Guidelines for Screening

(Available on the WWW: http://ojjdp.ncjrs.org/pubs/guidelines/contents.html)

The Violent Crime and Law Enforcement Act of 1994 directed the U.S. Attorney General to develop guidelines to help states adopt safeguards to protect children, the elderly or individuals with disabilities from abusive caregivers. In response, the Office of Juvenile Justice and Delinquency Prevention of the Department of Justice produced the Attorney General's Guidelines for the Screening of Persons Working With Children, the Elderly and Individuals with Disabilities in Need of Support in 1998. The guidelines emphasize that appropriate protections need to be tailored to meet the specific needs and circumstances of individual states and agencies, as well as the type of care being provided (e.g. policies developed by skilled nursing facilities will differ from those developed by agencies that provide volunteer companions to homebound seniors). The guidelines further propose a model for developing appropriate safeguards.

Under the model, screening for all caregivers must, at a minimum, include a written application with a signed statement by applicants, professional and personal references checks, and an interview. A three-step process is described for determining whether supplemental screening is warranted:

Step 1:

Identifying Triggers: The first step in determining the need for supplemental screening is to assess "triggers," which are defined as situations or circumstances that affect risk. Triggers include 1) the setting in which workers interact with clients, 2) the nature of their contact, and 3) special considerations. Assessing the setting involves taking into account whether workers are alone with clients, what other people will be present, whether the presence of others decreases the opportunity to abuse, whether workers will be closely monitored and supervised, and whether the contact will be in public or private. Triggers related to contact include the length and frequency of contacts between workers and volunteers and the nature of the relationship (for example, are the worker's responsibilities administrative or related to client care?). Special considerations are other factors that affect vulnerability such as clients' ability to communicate and pre-existing laws that require screening.

Step 2:

Assessing Intervenors: During this stage, decision-makers consider "intervenors," or factors that influence the availability or appropriateness of various screening options. These include the availability or accessibility of information (e.g. does the state permit or require criminal background checks), the urgency of the need (e.g. is immediate action needed to replace workers who are absent unexpectedly), liability concerns, the presence or absence of other protective factors, and agencies' financial and human resources.

Step 3:

Supplemental Screening Practices: During the last stage, decision-makers use the information described in steps 2 and 3 to choose what supplemental screening practices they will use. These include confirmation of the person's educational status; motor vehicle record checks; local, state or FBI criminal record checks; checks of central registries; checks of sex offender registries; home visits; psychological testing; alcohol or drug testing; and psychiatric history checks.

Office of the U.S. Assistant Secretary for Planning & Evaluation

This branch of the Department of Health and Human Services provides a focal point for consumer direction at the federal level. Its web site offers myriad reports on disability, aging, and long-term care policy.

http://aspe.hhs.gov/daltcp/hcbslist.htm

National Clearinghouse on the Direct Care Workforce

Developed by the Paraprofessional Healthcare Institute (see next page), the Clearinghouse collects, analyzes and disseminates information on the health care paraprofessional workforce and produces practice and policy-related resources for providers, consumers, workers, researchers and policymakers. The organization operates on the principle that enhancing the quality of direct-care workers' jobs is essential to providing high-quality care to consumers.

Contact:

NCDCW
349 East 149th Street, Suite 401
Bronx, NY 10451
Phone: 718.402.4138
Fax: 718.585.6852
email: info@directcareclearinghouse.org

Rehabilitation Research and Training Center on Personal Assistance Services (RRTC-PAS)

Funded by the National Institute on Disability and Rehabilitation Research (NIDRR), and operated by the World Institute on Disability, RRTC-PAS was created to explore how personal assistance services can promote economic self-sufficiency, independent living and full integration of people with disabilities into society. RRTC-PAS views personal assistance services as a civil right and explores models that enhance consumer control and choice. In the area of research, the Center is currently conducting a survey of states' PAS programs to determine the extent to which services are consumer-directed, a study investigating consumer involvement in Olmstead Decision implementation, and a study to explore ways to increase the quality and supply of the PAS independent provider workforce. In the area of training, the center provides basic training, technical assistance and information about PAS.

Contact:

World Institute on Disability
510 16th Street, Suite 100
Oakland, California 94612
Phone: 510.763.4100
Fax: 510.763.4109
Website: www.wid.org/pages/contact_wid.htm

InfoUse

A research firm specializing in health and disability issues, InfoUse is developing a multi-media program (web-based videos, CDs and hard copy manuals) to instruct seniors and people with disabilities in how to train and manage personal assistants effectively. It will have an interactive component that will enable the employer (the senior or person with a disability) to customize the training program, prepare a working agreement, schedules, etc. It also will serve as a basic training tool for agencies that provide personal assistant services.

Contact:

InfoUse
2560 Ninth Street, Suite 216
Berkeley, CA 94710
Phone: 510.549.6508
Fax: 510.549.6512
Website: www.infouse.com

Paraprofessional Healthcare Institute (PHI)

PHI is a national nonprofit health care employment development and advocacy organization with affiliates in five states. Its mission is to create jobs for low-income individuals (with a special emphasis on women who are unemployed or transitioning from welfare to work) and the provision of high quality care to elderly who are chronically ill or who have disabilities. The Institute facilitates the development of employee-owned health care enterprises, consumer-directed demonstrations, and employer-based training programs and coordinates a network to provide on-going support. It also provides consultation to consumers, labor and concerned providers in adopting employee-centered innovations in worker recruitment, training, job re-structuring and supervision. It advocates for public policy on behalf of direct-care workers, public assistance recipients and health care clients.

The Direct Care Alliance, operated by PHI, is a coalition of consumers, workers and concerned providers that was created to meet the urgent demand for high-quality paraprofessional caregiver services through advocacy, education and public awareness. DCA also advocates for legislative and regulatory policy.

Contact:

Paraprofessional Healthcare Institute
349 East 149th St., Suite 401
Bronx, New York 10451
Phone: 718.402.7766

ADDITIONAL RESOURCES

Proguard.org (A website of Guardianship Services of Seattle)

This website includes advice for selecting caregivers and a sample contract (adapted from one that was originally developed by Seattle attorney Suzanne Howle). Guardianship Services of Seattle provides financial and care management services to people with disabilities on a fee-for-service basis.

Website: http://proguard.org/contents.htm

Tips for Hiring Caregivers

Produced by the Attorney General of Pima County, Arizona, this soon-to-released brochure describes the various methods for hiring in-home helpers, alerts seniors that predatory individuals have been known to pose as caregivers, and offers suggestions for avoiding problems (e.g. don't give gifts or loans, always request receipts).

For more information, contact John Evans at:
Email: john.evans@AG.STATE.AZ.US

Legislative Blueprint for Action

National Association of Home Care

NAHC is the nation's largest trade association representing the interests and concerns of home care agencies, hospices, home care aide organizations, and medical equipment suppliers. In 2000, NAHC released a legislative agenda, which addresses such issues as the need for federal requirements for worker screening to be

strengthened to include federally-funded criminal background checks for all home visiting staff, developing quality of care standards for consumer-directed care, etc. The blueprint is available on NAHC's website at:

http://www.nahc.org/NAHC/LegReg/00bp/lbp05.html#v16.

Criminal History Clearance Training Program

Senior and Disabled Services Division (SDSD)
State of Oregon Department of Human Services

To assist nursing home administrators, residential care home operators, field officers who approve payment for independent providers, and others, SDSD has developed a two-and-a-half hour training program on criminal history clearance determinations. The program covers state laws related to background checks, fingerprinting, how to read FBI "fitness determinations," mitigating circumstances to consider when hiring and appeals processes.

Contact:

SDSD Provider & Consumer Services Unit
P.O. Box 14960
Salem, OR 97309-5045.

Client-Employed Provider Program Guides

Also developed by SDSD, this set of guides for in-home helpers and their employers describes the role of SDSD with respect to in-home helpers, the roles and responsibilities of workers and the persons for whom they work, conditions of employment and job standards. The manual for employers provides guidance on hiring practices, including suggestions for job descriptions, questions to ask during interviews with prospective employees, how to check references, and how to evaluate work performance. Both manuals (for employers and employees) contain sections on elder abuse. The manuals further contain information aimed at clarifying expectations between employees and employers with respect to such issues as confidentiality, gifts and working conditions.

Contact:

Senior and People with Disabilities
1.800.232.3020

Developing Training Programs on Elder Abuse Prevention for In-Home Helpers: Issues and Guidelines

This manual was written in February 2002 by Lisa Nerenberg for the National Center on Elder Abuse. It provides an introduction to in-home helpers, current sources of training and materials for members of this group, special considerations and a sample training outline.

Contact:

Elder Abuse Prevention Program
Institute on Aging
(formerly Goldman Institute on Aging)
3330 Geary Boulevard
San Francisco, CA 94118
415.447.1989 Ext. 513
Email: ElderAbusePrevention@ioaging.org

ADDITIONAL PUBLICATIONS ON ELDER ABUSE

If you find this publication useful, you may want to order other publications produced by the Institute on Aging for the National Center on Elder Abuse. Available publications include:

- *Mental Health Issues in Elder Abuse* (2000)
- *Helping Hands: The Role of Adult Protective Services in Preventing Elder Abuse and Neglect* (2000)
- *Forgotten Victims of Elder Financial Crime and Abuse: A Report and Recommendations* (1999)
- *Victims' Rights and Services: Assisting Elderly Crime Victims* (1999)
- *Prosecution and Protection: Understanding the Criminal Justice System's Role in Preventing Elder Abuse* (1998) Co-authored by Candace Heisler, JD.
- *Communities Uniting: Volunteers in Elder Abuse* (1997)
- *Financial Abuse of the Elderly* (1996)
- *Older Battered Women: Integrating Aging and Domestic Violence Services* (1996)
- *To Reach Beyond Our Grasp: A Community Outreach Guide for Professionals in the Field of Elder Abuse Prevention* (1995)
- *Building Partnerships: A Guide to Developing Coalitions, Interagency Agreements, and Teams in the Field of Elder Abuse* (1995)

Also available from the Institute on Aging:

- *Serving the Older Battered Woman, a Conference Planning Guide* (1996, $30)
- *Domestic Violence and the Elderly: A Cross Training Curriculum* (1998, $20)
- **Video:** *When Help Was There: Four Stories of Elder Abuse* (2000, $79.99)

- Each book is available for $15 (California residents, please add 8.5% sales tax)
- Bulk rates are available
- Make checks payable to:

Institute on Aging
(Federal tax Identification Number 94-2978977)

Attention: Elder Abuse Prevention Program
3330 Geary Boulevard
San Francisco, CA 94118

- Phone: 415.447.1989 Ext. 519
- E-mail: ElderAbusePrevention@ioaging.org