

Direct Care Alliance Policy Brief No. 9

No Excuse for Abuse

By Elise Nakhnikian

Frightened by the changes she sees in her husband, whose dementia is progressing rapidly, and wounded by his tendency to ignore or resist her, Laura yells at him to shut up when he insists on going “home” to the house where he lived as a boy. “I can’t take it any more,” she tells him. “You’re nothing but a burden to me! Why don’t you just die?”

Mary, a nursing home CNA rushing to get through her daily tasks, gets stuck in a standoff with Wanda, who doesn’t want to take the shower Mary’s scheduled to give her. When Wanda strikes out at Mary, scratching her face, Mary hits back without thinking, pushing Wanda so hard that she falls.

There’s no excuse for that kind of abuse, or for any of the abuse endured by people with physical or mental disabilities at the hands of the caregivers they depend on. Yet simply vilifying the abusers won’t make the problem go away. In fact, it can make things worse.

While some caregivers are uncaring or even cruel, treating all who abuse as sadistic helps push the problem underground. People who witness abuse but empathize with the abuser may be reluctant to report what they’ve seen, fearful of tarring a good person’s reputation. Family caregivers judged harshly for their mistreatment of relatives may isolate the care recipient further, withdrawing from health care professionals and others who could have intervened. Professional caregivers may hide their frustration and lapses in self-control rather than seeking the supervisory guidance or training they need.

Demonizing abusers also makes it harder to find the high-quality caregivers we need. A widespread misperception that paid direct care workers are responsible for most care recipient abuse tarnishes that honorable profession, making it more difficult for caring, conscientious workers to commit to it long-term.

In order to reduce abuse, we must understand and address its root causes, looking at both professional (formal) and family (informal) care as it is experienced by caregivers and care recipients. In this policy brief, we summarize what we know about the abuse of elders and people with disabilities. We look at the complex web of interlocking cause and effect that often lies behind the act, making it impossible to effectively help care recipients without also helping their caregivers. We also recommend steps that both employers and policymakers can take to alleviate the problem.

Defining the Problem

About 12.7 million people receive long-term care services every year in the United States, 1.8 million of them in nursing homes and the rest in their own

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The Direct Care Alliance

- The Direct Care Alliance is
- the national advocacy voice
- of direct care workers. We
- empower workers to speak out
- for better wages, benefits,
- respect, and working
- conditions, so more people
- can commit to direct care as
- a career. We also convene
- powerful allies nationwide to
- build consensus for change.

homes or other community settings. These care recipients rely on paid and/or unpaid caregivers for assistance with at least one activity of daily living (eating, bathing, dressing, going to the toilet, and transferring from one place to another). They may also need assistance with instrumental activities of daily living, which include meal preparation, shopping, light housework, money management, taking medication, and more. The great majority—92 percent—of the 10.9 million who receive care in their homes get unpaid help from family members and other informal caregivers, while just 13 percent receive paid help.¹ (Those two numbers add up to more than 100 percent because some receive both types of care.)

Unpaid services are generally provided by spouses, children, in-laws, and other relatives. Paid services are generally provided by direct care workers, an umbrella term developed to include the nursing assistants, home health and home care aides, personal assistants, and other caregivers who provide an estimated 70 to 80 percent of the hands-on care in residential and home- and community-based long-term care.²

Most of that care is provided competently, caringly, even lovingly. But providing personal care is an often intimate interaction that touches on primal issues such as privacy, dignity, and self-determination. Care provided by family members comes with an added layer of personal history, which may include or inspire conflict, hurt feelings, or even violence.

DEFINITIONS AND DATA

According to a recent panel convened by the U.S. National Academy of Sciences (NAS), elder abuse consists of two types of incidents: “(a) intentional actions that cause harm or create a serious risk of harm (whether or not harm is intended), to a vulnerable elder by a caregiver or other person who stands in a trust relationship to the elder, or (b) failure by a caregiver to satisfy the elder’s basic needs or to protect the elder from harm.”³ Abuse may be physical, psychological, sexual, or financial. Its victims include younger people with disabilities as well as elders who rely on personal or long-term care services.

The wide variety of care recipients at risk for abuse, the variety of settings in which they receive care, and the considerable room for interpretation within the NAS definition all contribute to the difficulty of developing an accurate measure of the extent and nature of care recipient

abuse, as does the fact that there have not been many attempts to do so. A recent GAO report on abuse of elders receiving home- and community-based care says the four best available studies likely underestimate the extent of the problem, since “[m]ost did not ask about all types of abuse or include all types of older adults living in the community, such as those with cognitive impairments.”⁴

As for institutional settings, reliable data are so rare that Mark Lachs and Karl Pillemer summarized only research on abuse committed in home- and community-based settings in a 2004 summary and analysis of research on elder abuse, concluding that “there is almost no scientifically credible empirical research about abuse in institutions.”⁵

Abuse may be particularly difficult to measure in nursing homes because it can be difficult to distinguish the second part of the NAS definition—failure by a caregiver to satisfy the elder’s basic needs or to protect the elder from harm—from the neglect often suffered by residents in understaffed facilities. As one study notes: “In surveys, up to 95 percent of nursing home residents who were interviewed reported that they had recently themselves experienced neglect or witnessed other residents being neglected. Complaints included leaving residents wet or soiled with feces, shutting off call lights without providing assistance, not turning and repositioning residents, and not assisting residents with eating and drinking. Nursing and aide staff are also aware of the widespread nature of patient neglect, citing times of short staffing and shift changes as times when neglect is more likely to occur.”⁶

It can be equally difficult to reach agreement on what constitutes abuse by a family caregiver. Some families would find nothing unusual, let alone objectionable, in what Laura says to her husband in the opening paragraph of this brief, while others would find it shocking. A British survey of family caregivers of people with dementia, which found that about a third had committed “important” levels of abuse in the past three months, noted that many intimate relationships include a strain of verbal or physical abuse. “It is unsurprising that disagreement exists about what form of behaviour constitutes elder abuse and what is part of normal family relationships,” the researchers observed.⁷

As a result of all these factors, estimates of the extent of the problem vary widely. The National Research Council estimated in 2003 that 1 to 2 million elders had been subject

to abuse, much of it financial, while the sources surveyed by Lachs and Pillemer reported that anywhere from 2 to 10 percent of elders in home and community settings were victims of abuse. Meanwhile, a survey of studies of abuse of people with disabilities of all ages in their own homes found evidence of considerably higher incidence rates by personal assistance services (PAS) providers.

PAS abuse reported by women included 49 percent having their provider arrive late or leave early, 41 percent having been insulted or put down, 36 percent having their money stolen, 14 percent having equipment immobilized or broken, 14 percent having their medication withheld, stolen or overdosed, 14 percent having been physically abused, and 6 percent having been forced into unwanted sexual activity. PAS abuse reported by men included 44 percent having been insulted or put down, 34 percent having their provider arrive late or leave early, 14.9 percent having their medication stolen, 12 percent having checks or credit card payments forged, 10 percent having equipment immobilized or broken, 9 percent having been hit, kicked, slapped or otherwise hurt, and 8 percent having been forced into unwanted sexual activity.⁸

Another estimate of the extent of the problem may be found in the reports filed by state Adult Protective Services (APS) agencies. APS agencies received 378,128 reports of abuse in 2000, of which they were able to substantiate less than half (166,019). The most frequent allegations substantiated involved self-neglect (41.9 percent), physical abuse (20.1 percent) and caregiver neglect (13.2 percent). Well over half the total incidents reported (60.7 percent) took place in the home of the person abused and just 8.3 percent in institutional settings, with another 6 percent in “mental health/mental retardation settings” and the remainder unclassified by setting.

Not all states classified the victims of substantiated reports by age, but in those that did, nearly three-quarters (71 percent) of the victims of caregiver abuse were 60 and over, while about a quarter (26 percent) were younger adults between 18 and 59 years old.⁹

THE SILENT MAJORITY?

Adding to the difficulty of gathering data on the problem is the fact that abuse is believed to be grossly underreported.

When abuse occurs in private, witnessed only by the people involved, the abusers have obvious reasons not to report it. The people they abuse often fail to report as well, perhaps because they are embarrassed to tell anyone, fearful of retaliation if they do, emotionally dependent on the abuser and unwilling to risk alienating them, or simply unable to articulate the problem due to dementia or other cognitive impairments.

Even abuse that is witnessed by others often goes unreported. As one study points out, “Facility staff and family members might be uncomfortable reporting abusive behavior regardless of assurances of confidentiality. Patients and family members might fear retaliation by nursing home staff or other caregivers.”¹⁰

Co-workers or family members may also be cowed or co-opted into accepting abuse, convinced that it is normal or at least unavoidable. One study found that workers who witness abuse in institutional settings often do nothing because they do not know how or to whom to report it.¹¹ Another found that some staff simply did not know how to identify abuse or determine whether the situation needs to be reported, and others encountered institutional barriers to reporting. Others refrained out of concern for their colleagues, feeling that abuse occurred only because they were overworked, inexperienced, and/or frustrated from dealing with difficult residents, so it would be unfair or unproductive to report them.¹²

The Face of Abuse

Though we don’t know precisely who commits abuse, the great majority are most likely family caregivers. In the cases substantiated by the APS in 2000, 61.7 percent of the perpetrators were family members. (Spouses or intimate partners made up the biggest single group at 30.2 percent of the total, followed by adult children at 17.6 percent.) Facility/institutional staff perpetrated only 4.4 percent of substantiated reports, not much more than friends and neighbors (3 percent).¹³ No wonder that British survey of family caregivers of people with dementia concluded: “[A]ny policy for safeguarding vulnerable adults must consider strategies directed towards families who provide the majority of care for older people, rather than exclusively formal carers.”¹⁴

The high percentage of family caregivers found among abusers is probably at least partly due to the fact that

they provide most of the care. It may also have to do with the emotions and stresses that often trigger abuse.

WHY ABUSERS ABUSE

Some people who abuse care recipients are indifferent to their well being, while others mean well but lash out in response to negative feelings they cannot control. One researcher has suggested that these two types of abusers can be categorized as sadistic and reactionary.¹⁵ Research tends to focus on reactionary abuse, which is probably by far the more common type. The most common theory as to what may cause it is caregiver stress.

According to this theory, abuse often occurs when caregivers are emotionally and/or physically overburdened, since burned-out caregivers can easily develop negative attitudes towards care recipients and their “problem” behaviors, which in turn create a toxic combination of frustration, exhaustion, and resentment that can lead to abuse.¹⁶ Inadequate training in how to handle difficult situations and particular conditions such as dementia can also cause stress that leads to abuse, as can a tension-fraught relationship between caregiver and care recipient.¹⁷ (Family caregivers who had good relationships with the people they are caring for in the past report less stress and are less likely to become violent even when the demands of caregiving are extremely high.¹⁸) Even stresses experienced outside the job, such as worries about finances or troubles at home, may increase the likelihood of abuse.

TRAPPED IN A NEGATIVE FEEDBACK LOOP

But frustration and stress are not one-way streets. Elder abuse is increasingly being seen as the result of complex and stressful dynamics between caregiver and care recipient, with one party’s actions and attitudes affecting the other and creating a “reactive pattern or feedback loop.”¹⁹

Simply living with a caregiver increases a care recipient’s risk of being abused, with care recipients who live alone being least at risk for abuse. (The exception to this rule is financial abuse, the majority of whose victims live alone.) What’s more, abusers tend to depend more on the people they abuse for financial support and housing than non-abusers do on the people they care for. Lachs and Pillemer explain that dynamic by noting: “Abuse results in some cases from attempts by the relatives (and especially adult offspring) to obtain resources from the victim.

Moreover, situations have been identified in which a tense and hostile family relationship is maintained because a financially dependent son or daughter is unwilling to leave and thus lose parental support.”²⁰

A history of violence between caregiver and care recipient may feed current conflicts. In one study of people with dementia, those who had been violent toward their caregivers before developing the disease were more likely to be abused than those who had not.²¹

Dementia is in itself a risk factor: Elders with dementia are more likely to be abused than those without cognitive impairments. This is partly because they may be unable to “defend themselves from or even recognize the abuse or neglect,” as the GAO’s report points out, but the primary cause appears to be behavior on their part that causes frustration, anger, or even violence in their caregivers and triggers a reactive pattern.²² Among people with dementia, those who exhibit aggressive behavior toward their caregivers are at greatest risk of both physical and psychological abuse, “whether it is as a reflex, in self-defense, or in response to frustration.”²³

Ironically, those same impulses—reflexes, self-defense, and frustration—motivate the aggressive behaviors that started the vicious cycle. People with dementia tend to lash out at their caregivers when they feel powerless, frightened, and/or frustrated and are unable to communicate effectively through any other means. An estimated 57 to 67 percent of people with dementia abuse their caregivers either verbally or physically, most often while receiving intimate care,²⁴ and their aggression often breeds aggression. One study found that 26 percent of caregivers who were physically abused by people with dementia abused their care recipients in return, while only 5 percent of those who were not abused committed abuse.²⁵

Even when they are not violent or aggressive, people with dementia often exhibit behaviors that their caregivers find particularly stressful. These include lack of impulse control, volatility, anger, self-absorption, inability to show enthusiasm, poor concentration, paranoia, withdrawal, repetition of words or actions, bizarre behavior resulting from hallucinations, severe mood swings, wandering, incontinence, sleeplessness, refusal to eat or take medications, calling the police, invading the caregiver’s privacy, noisiness, “vulgar habits,” and the decline of mental functioning toward the end of the day that is commonly known as sundowning.²⁶

RISK FACTORS FOR BEING ABUSED

Several risk factors for being abused have already been cited: living alone, having dementia, having a history of violence with one's caregiver, and providing housing or financial assistance to one's caregiver. In addition, victims of elder abuse are more likely than non-victims to be isolated from friends and relatives (other than the abusive caregiver). As Lachs and Pillemer point out, such isolation can lead to abuse by increasing family stress. It also makes it less likely that the abuse will be discovered and stopped.²⁷

RISK FACTORS FOR BEING AN ABUSER

Abusers are more likely than nonabusers to have a problem with drinking or drugs, to be depressed, or to have a history of psychiatric illness.²⁸ They are also more likely to report being stressed and socially isolated than nonabusers, although their actual stress and isolation levels may not appear higher when measured objectively.²⁹

Preventing Abuse

The best way to prevent abuse may be to offer more support to caregivers.

WORKING CONDITIONS

Testifying before the U.S. Senate Committee on Finance in 2002, Catherine Hawes noted "remarkable consensus across diverse studies and surveys of stakeholders" that the following three factors contribute to the problem of abuse and neglect in long-term care facilities:

- **Staffing shortages**, which both lead directly to neglect and create stressful working conditions that increase the risk of abuse.
- **Staff burnout**, which is often a result of staffing shortages, mandatory overtime, and the need to work more than one job to survive financially.
- **Poor training**, particularly on understanding dementia and managing the challenging behaviors it can cause.

"I should note that if I were going to do only one thing to reduce abuse and neglect, it would be to increase staffing in the nation's nursing homes," Hawes concluded.³⁰

While staffing shortages are not much of an issue for personal assistance services (PAS) providers in home- and community-based settings, their wages and benefits are even worse than those of nursing assistants in nursing homes, and the burnout caused by that stress often leads

to abuse, according to a literature review by Laurie Powers and Mary Oschwald. "If they are to have a chance to prevent and stop violence in their lives, individuals with disabilities who use PAS must be able to offer competitive wages and benefits so they can have viable options for support providers," the authors conclude.³¹

In addition, poor supervision is a problem for professional caregivers in all settings. The nurses who supervise direct care workers typically have good clinical skills but no training in how to manage the people who report to them, let alone help them deal with stressful situations.³² As a result, direct care workers dealing with a "difficult" situation or client can rarely count on advice or assistance from the people they report to, so they often keep their problems to themselves, devising ad hoc solutions.

TRAINING

As Catherine Hawes noted in her Senate testimony, lack of training is often cited as a contributing factor to abuse. Effective training could prevent some, if not all, of the abuse that springs from frustration as caregivers struggle to deal with "difficult behaviors" they don't know how to handle and/or avoid triggering.

Unfortunately, the family caregivers who provide most of the hands-on care rarely get much training on how to do it, and the professionals who do the rest don't get much more.

The only direct care workers required by the federal government to have any training at all are those who work in Medicare or Medicaid-funded nursing homes or home health agencies—and even they must undergo only 75 hours of initial training and 12 hours a year of continuing education. Some states increase the number of hours required of these nursing home nursing assistants and home health aides, and some require training for direct care workers in other settings. But even the most extensive training rarely exceeds three or four weeks,³³ hardly enough time to learn how to understand and respond appropriately to the range of needs presented by frail elders and younger people with disabilities, let alone to learn how to identify and report abuse.

Some employers address that information gap by offering their own abuse prevention training. A few partner with ombudsmen or consumer advocates,³⁴ while others design their own programs. The Jewish Home and Hospital Lifecare System in New York City, for

example, developed a “train the trainer” program to help its clinicians teach home health aides how to identify abuse and neglect and build up the trust crucial to good communication between the aides and the licensed staff. The program was initiated after a initial study found that aides often observed abuse of home care recipients by their family members but didn’t report what they saw, or reported it only to find that the agency’s professional staff had failed to follow up.³⁵

A complete set of abuse and neglect prevention training modules developed with funding from the Centers for Medicare and Medicaid Services is available for download free of charge on the PHI website.³⁶ The training program was developed by BEAM (Bringing Eden Alternative to Michigan), Michigan State University, and PHI with leadership from the Michigan Office of Services to the Aging.

HIRING

While preventing reactionary abuse is an ongoing challenge, employers can weed out sadistic abuse by hiring the right people, screening for sensitivity, interest in working with elders or people with disabilities, good interpersonal and communications skills, and other traits that distinguish conscientious caregivers. A PHI issue brief on the subject offers detailed tips on hiring direct care workers, including where to look for candidates, how to structure the interview process, and what questions to ask.³⁷

One part of that screening process is doing the criminal background check that many states require for prospective caregivers. These checks are no magic bullet, and care must be taken not to saddle low-income caregivers with the cost of the tests, or to allow poorly selected criteria to eliminate good prospective caregivers due to past mistakes that have no bearing on how they would perform the job. Properly constructed and administered, however, background checks are a useful tool. The Centers for Medicare and Medicaid Services is funding a pilot program aimed at creating a nationwide system of criminal background checks for prospective hands-on caregivers. Six states are currently participating in CMS’s National Background Check Program, and more may join soon.

REPORTING SYSTEMS

Another key to stopping abuse is reporting it promptly whenever it is detected and responding promptly and

effectively to those reports. Our long-term care system includes checks and balances intended to facilitate that process. Unfortunately, they do not always work as intended.

Many categories of medical and social services professionals are required to report abuse when they encounter it, but they often fail to recognize or report it, and the victims themselves cannot always be counted on to ask for help. People with cognitive disabilities may not know that they are being abused, or be able to get other people to believe them, while people who are cognitively intact may be reluctant to complain of mistreatment for fear of alienating, angering, or endangering the caregivers they rely on and may even love. People receiving government-funded care at home face another dilemma that may discourage them from reporting abuse: If they have children, they risk being declared incapable of providing adequate protection and losing custody to child protective services.³⁸

All states must investigate complaints of abuse, neglect, or misappropriation of resident property by any nursing assistant as part of the maintenance of the nurse aide registries they keep, which keep track of all nursing assistants in nursing homes that participate in Medicare or Medicaid. In addition, state APS agencies, social service agencies, and long-term care ombudsman offices must record and investigate reports of adult or elder abuse. But the agencies tasked with follow-up are often stretched as thin as the caregivers they investigate. According to the recent GAO report:

APS program officials have found it difficult to ensure adequate staffing levels. Program officials in three states we contacted told us they do not have enough funding to hire additional caseworkers to handle increasing caseloads. According to our survey, 33 states indicated there have been freezes on hiring APS caseworkers in the last year, and 25 states said that APS caseworkers had been subject to furloughs. In addition, APS program officials told us that when funding decreases, training for caseworkers is often reduced or eliminated.³⁹

The GAO also reports that APS program officials “do not have sufficient resources to develop and implement public awareness campaigns,” although they recognize the need for public education about elder abuse.

Recommendations

FOR EMPLOYERS

Attract and keep caring workers by improving direct care jobs and hiring practices, and provide them with supportive supervision

- Screen potential caregivers for the maturity, compassion, and judgment that are needed to do the job well.
- Hire enough staff, and give them enough autonomy, so they can provide unhurried, individualized care.
- Provide adequate compensation, benefits, and opportunities for advancement.
- Train the nurses who supervise direct care workers in how to help them handle challenging behaviors, defuse tense situations before they get out of hand, and deal with their own depression and burnout.

FOR FEDERAL AND STATE POLICYMAKERS

Mandate adequate funding for caregivers

- Ensure that the state and federal programs that reimburse for long-term care services disburse adequate funding to provide high-quality care.
- Require all organizations that accept government funding for long-term care to hire an adequate number of caregivers, compensate them fairly, and offer them appropriate benefits.

Mandate and fund better caregiver training and public education

- Mandate and underwrite abuse prevention training for professional caregivers, including what constitutes abuse, how to provide individualized care for people with dementia and other challenging conditions, and stress reduction and conflict resolution techniques. Make the same training available to informal caregivers and create a public outreach campaign to let them know it's available.

Support family caregivers

- Ensure that family caregivers have access to support groups, respite care, and services such as transportation for care recipients, as well as the training described above.

Empower care recipients

- Create and disseminate an abuse tool kit for people with disabilities. This might include information about

what kind of caregiver behavior is and is not permissible, self-administered abuse screening tools, emergency phone numbers, and tips for safety planning.

Institute a fair and effective nationwide system for criminal background checks

Institutionalize CMS's National Background Check Program as a nationwide screening system for all prospective direct care workers hired by third-party employers. Ensure that it do the following:

- Include a search of all available state direct care worker registries, as well as state and federal criminal history records.
- Minimize the likelihood of screening out good candidates by conducting research to find what crimes should disqualify candidates and for how long after committing the crime they should remain ineligible for care work.
- Allow applicants who committed a disqualifying crime to attempt to demonstrate that they are qualified for the work, at no cost to them.
- Ensure that any disputes over the accuracy of the findings are reviewed and decided promptly, at no cost to the applicant.
- Allow care recipients who hire their own workers rather than going through an agency to hire people who could not pass the criminal background check required of a third-party employer if they choose to do so.

Facilitate the reporting and investigation of complaints

- Improve training for the health care and social service professionals who are mandated to report abuse, so they are better prepared to identify and report potentially abusive situations.
- Ensure that abuse reporting systems are easy to access and anonymous.
- Ensure that Adult Protection Services agencies have adequate funding and staff to thoroughly investigate all reports of abuse.
- Ensure that people receiving services at home will not be placed in an institution or have their children or pets taken away if they are being abused, so they need not fear reporting abuse.
- Provide 24-hour crisis hotlines for victims of caregiver abuse.

Fund research on incidence, causes, and interventions for abuse of elders and people with disabilities

More data is needed on:

- Demographics of abusers and the people they abuse.
- Prevalence and type of abuse in institutional as well as home- and community-based settings.
- Risk factors and protective factors for various forms of abuse, including neglect, psychological mistreatment, sexual abuse, and financial abuse.
- Effectiveness of various forms of abuse interventions.

Pass the Elder Abuse Victims Act

This bill⁴⁰ would create an Office of Elder Justice within the U.S. Department of Justice, which would evaluate ongoing efforts to reduce abuse and review state-level efforts to address the issue. It would also mandate an annual nationwide collection of data on elder abuse and establish a grant program to help states investigate and prosecute cases while minimizing trauma to the victims.

Conclusion

The personal, often intimate nature of caregiving relationships can make it difficult to define, detect, and deter the abuse of elders and people with disabilities by the caregivers they rely on. Nonetheless, there are a number of steps that employers and policymakers can take to support good care and prevent abuse. They can make it easier for care recipients to report abuse without fear of reprisal. They can improve access to affordable respite care and other support for informal caregivers. They can see to it that professional caregivers are adequately screened, compensated, and supported on the job, and that staffing levels in long-term care facilities are sufficient to meet resident needs. They can give all caregivers, whether formal or informal, access to training on how to recognize and prevent elder abuse and neglect. They can improve the systems that facilitate the reporting and investigation of complaints. And they can fund research to determine the incidence and nature of abuse, and the effectiveness of various interventions.

End Notes

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