Elder Abuse & Family Caregiving: Lessons Learned From Child Welfare

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The author recommends the Project SAFE model for elder abuse including intensive training for local adult protective services to recognize the crucial distinction between "abusive' versus "burned-out" caregivers; and advocates for supportive services for burned out caregivers so families can be preserved or reunited.

According to the Kansas City, Missouri (AP) Stanley Reimer kissed his dying wife Christi goodbye and threw her off their fourth floor balcony because he could no longer afford her medical care. Reimer is serving a life sentence for murder and will likely die in prison. Neither his death certificate nor Christi's will say they died of "caregiving. But did they? Before I join the ranks of those demonizing Stanley, I have some serious questions. How many agencies, professionals, friends, family, and neighbors did these two suffering souls reach out to? How many requests for help were turned down? Who might, should've, could've intervened? What services might have been put in place to prevent this unthinkable tragedy?

The sordid revelations in 2006 of the alleged abuse and neglect of 104-year old New York philanthropist and society queen, Brooke Astor, by her son, Anthony Marshall, brought the subject of elder abuse into exceptionally sharp focus. The new biography of Brooke Astor's life, *The Art of Giving*, says: "If it could happen to Brooke Astor, it could happen to anyone."

CAREGIVERS AT RISK

With the deterioration of the health care system more is being piled on the already breaking backs of family caregivers. Pushed to the brink by the relentless demands of caregiving, sleep deprivation, self neglect, debilitating anxiety and depression some family caregivers snap mentally others collapse physically. Each time a caregiver snaps under the pressure, two more people (patient and family caregiver) are catapulted into already overburdened systems. Is Adult Protective Services (APS) in every state trained to recognize the risk and resiliency factors to recognize, intervene and prevent such tragedies?

Researchers have found that the immune system of the caregiver deteriorates with the patient. Studies show that anxiety and depression reach debilitating proportions as family caregivers abandon self-care in order to respond to the needs of elderly relatives. Most caregivers have long days, nightly interruptions and little or no help. When caregivers—whose great crime was stepping up the daunting tasks of caregiving—collapse under such pressures, is it fair to kick them to the curb with accusations and convictions?

Kathleen's father has Alzheimer's. "I hated myself more as my resentment against my

poor helpless father grew worse. And, I'd promised to never put him in a nursing home."

Carrie, whose mother had diabetes and heart disease, says, "I felt so guilty for yelling at my sweet mother. But I hadn't slept in weeks because mom cried a lot during the night and needed to changed. And I couldn't find reliable affordable help."

In one study caregivers readily and painfully admitted they yelled, threatened, slapped or shoved their loved one. Caregiver's berate themselves for their acts of unkindness, their despair deepens, and they become less and less able to control their frazzled emotions. Just like parents in the child welfare system, otherwise loving family caregivers for adults are worried sick about their loved one, financial concerns, hunger, sleep deprivation, and their own health. They hate themselves for losing their patience, screaming and name calling.

DATA ON ELDERS

Data collection on elder abuse is problematic due to the absence of reporting, underreporting, and varying differences in definitions and data collection across states, but the number of elders abused in estimated five times the number reported. According to the National Center on Elder Abuse, based on the best available estimates in 2000, between 1 and 2 million Americans age 65 or older were injured, exploited, or otherwise mistreated by someone on whom they depended for care or protection. The Survey of State Adult Protective Services shows a steady increase in the number of domestic elder abuse reports and the majority of those are substantiated by investigation. As the boomers age that number will mushroom. Meanwhile, as data collectors continue to wrestle with the challenges of faulty and scanty data, our seniors and their family caregivers desperately need interventions like Project SAFE.

ORIGINS OF PROJECT SAFE

Though Project SAFE has its origins in child abuse it is an ideal model for effective statewide adult protective services (APS). Child prevention studies conducted in the early 80s found that otherwise patient and loving protective parents, upon suffering tragedies such as job loss, medical crises, divorce, and other pileups of pressure became progressively more irritable, impatient and soon resorted to yelling and name calling. Many parents woefully admitted to hitting their children. Without emotional decompression and help to address the tragedies, the intensity and duration of violence directed at their children escalated.

Project SAFE began looking at parents to discern which might benefit from services to keep their families together and has yielded amazing outcomes. For example, follow-up contacts even years later showed that 81% of the SAFE families remain stabilized in recovery, with only 6.25% subsequent reporting to child welfare. Since its origins in the 1980s, the SAFE model in Illinois saved millions of state dollars annually, and for that reason additional funding was allocated, expanding from 4 pilot sites to 95 programs across Illinois throughout the 90s. Soon I started assisting other states in the implementation of the SAFE Model and continue consulting, training & technical assistance as safe continues to spread across the nation.

The SAFE model has shown beyond a doubt the value of family preservation and

reunification efforts with approximately timed services, identifying risk and resiliency, assessing addiction severity, and identifying the crucial distinction between burned-out versus abusive caregivers. Today the SAFE model can serve APS in the same way, preventing vulnerable elders from being torn from their homes, by providing both the elder and the weary caregiver with adequate and timely services so the family can remain together.

When all the components of SAFE are firmly in place, this time tested model helps those in need, even families ravaged by addiction, poverty, divorce, job losses, foreclosures and the relentless demands of caregiving can be preserved or reunited. Preventing broken hearts of families on the verge of being torn from each other is priceless and easily adaptable to APS.

COMPONENTS OF THE SAFE MODEL

The SAFE Model's success rests solidly on the team's ability to accurately assess each family for risk and resiliency factors along a continuum. This includes distinguishing between homes in need of supportive services versus abusive homes where elders (or the abuser) must be removed. As teams move through the stages of collaboration, they become progressively more proficient at rapidly identifying and responding to families with appropriate timely interventions and services.

Beginning with experiential skill building training to fully understand the model, SAFE can be implemented in any state as long as all of the following key components are in place: Collaboration, referral, outreach, interventions for both elder and caregiver, case management, case coordination, training (formal & informal) and technical assistance, funding and evaluation.

- Collaboration includes all the key players: policy-makers, funding and decision-makers, representatives from systems and services. Collaborative teams soon embrace the collective power of "Doing-together-what-each-cannot-do-alone."
- Referral processes use state-specific forms and guidelines. Record-keeping parallel's families' movements across services with useful state specific forms and guidelines.
- Outreach includes regular ongoing contact with the elder and their caregiver throughout their supportive services.
- Case management is dynamic, identifying the ever-changing service needs of both elder and family caregiver.
- Case coordination occurs weekly in joint staffings, care plan meetings and ongoing communication between face to face meetings.
- Training is both formal & informal throughout the life of SAFE to influence policy changes, and transfer knowledge, skills and practices across the state.
- Ongoing technical assistance is crucial so the model doesn't break down from bumps in the road such as turnover rates, retiring champions or other significant changes that occur before the model has been institutionalized.
- Funding – SAFE was initially funded through a federal CSAT grant. After seeing tremendous cost effective outcomes reduce financial burden and human tragedy, state funding was re-routed to SAFE saving the state millions of dollars per year.
- Evaluation outcomes were so impressive that after the federal grant ended, the state funded evaluation to track emerging trends that impacted service delivery.

The SAFE Model not only rebuilds families, but transforms systems and services. SAFE is highly effective when all systems involved share ownership, commit time and resources, and when SAFE is woven through the unique fabric of regional and cultural differences in a state.

CASES FOR DISCUSSION

Patient with Bruises

Donna caring for her brother dying of cancer says. “My pleas-for-help were ignored, but seeing bruises all over my brother’s stomach, family members accused me of physical abuse. I was livid and so angry I did a terrible job of explaining that the bruises were from the heparin shots. They wouldn’t listen.” Fortunately for Donna a neighbor who was a nurse explained to the family that heparin shots cause bruising at the location of the shot. The family still wouldn't help, but seeing the nurse as a higher authority, they backed off. Seeing Donna buckling under the demands all alone, the nurse convened a care team of neighbors and friends to help her. What would’ve become of Donna and her brother, if the nurse hadn’t intervened on her behalf?

Bed Sores

“Take her! I can’t stand it anymore.” Cried Liz. “You won’t help. All you do is criticize!” A complaining aunt accused her of neglecting her mother’s bed sores. Fortunately, at that moment, a hospice volunteer showed up and verified that the 60-year-old daughter/family caregiver turned her mother regularly and changed her throughout the day. Between the mother’s endless demands, the daughter had made hundreds of calls in search of help, but her own back problems and a host of other health issues were taking a toll. The unfair accusation had come close to pulling Liz and her mother apart, but hospice saved the day. Hospice arranged for a special mattress to reduce bed sores, increased home health visits and added more volunteers to support both mother and daughter. How many people like Liz are out there who were not lucky enough to have a hospice volunteer show up?

Elder Abuse and Addiction

In SAFE over 80% of families in child welfare were dealing with substance abuse. In elder abuse cases it is estimated that 50% of families have some form of substance misuse. The stigma associated with substance misuse can launch a quick rush to judgment and accusations of financial exploitation, neglect and mistreatment, that are not necessarily true.

A neighbor called to complain about the son yelling at his mother, and that he’d left her alone on numerous occasions. The investigator reported seeing empty beer bottles. During questioning the mother looked nervous and wouldn’t look at the investigator who assumed the mother feared retaliation from the son. In reality, she was afraid the investigator was there to put her in a nursing home. The stressed-out son drank a few beers every night, but the substance abuse assessment did not reveal alcoholism. He left her alone when he needed to go to the pharmacy or grocery store and couldn’t get anyone to stay with her. Mother and son, though close, had tense moments, as most relationships to. Their immediate need was respite for the son

and helpful services for the mother. Recognizing he was at risk of developing a drinking problem, as he and his mother got help, he stopped drinking.

With the high rate of substance misuse, it's important to have an addiction professionals on the team. One family caregiver suffering from stress, insomnia, anxiety and depression was being over-medicated by prescriptions from her doctor, which was *causing* a substance misuse problem that didn't exist before caregiving. A physician who specializes in addiction, helped get her off all the medications and switched her to non addictive natural supplements.

While doing workshops I've met caregivers with years in recovery who relapsed from the pressures of caregiving. One woman with eleven years in recovery was prescribed medications that are not safe for people in recovery. The particular medication impacted the part of the brain that set off cravings and loss of control that lead her back to drinking. She needed respite and services so she could stop worrying about her loved one so she could get back to self help meetings and the needs of her recovery. What biases or assumptions do we have about substance misuse that might stand in the way of being helpful?

SUMMARY

While I support swift justice for the greedy, heartless and cruel who exploit the vulnerable elderly, a truly effective and humane service model must broaden its scope to include both patient and caregiver, all their strengths, weaknesses, resources, and unmet needs. When we misinterpret a situation or the caregiver/recipient relationship, regardless how well intended, we become the interlopers. Caregivers who sacrifice years of their lives, selflessly caring for a loved one, losing jobs, giving up friends, hobbies, interests, and activities they once enjoyed, are at risk of becoming the second victim of their loved one's condition unless we intervene with high quality comprehensive collaborative models like Project SAFE.

Bio Sketch

Maya Hennessey is a consultant, trainer, addictions specialist, caregiver advocate and author of *If Only I'd Had This Caregiving Book*, on guiding family caregivers to create an effective network of support. Maya was statewide manager of Project SAFE and featured in the Bill Moyers PBS-TV series titled *Close To Home* on the power of collaboration to rebuild families. Maya is the Midwest Volunteer coordinator for the National Family Caregivers Association (NFCA) and has served on high level policy making committees such as the Real Choice Systems Change project, assisting individuals in nursing homes to get in-home services so they could live successfully in the community. Maya is a dynamic public speaker who has presented thousands of experiential skill building workshops for addictions, child welfare, criminal justice, aging, and family caregiving. www.mayahennessey.com, phone: 773-878-4870.

RESOURCES

National Citizen's Coalition for Nursing Home Reform (NCCNHR) www.nccnhr.org
NCCNHR is a coalition of concerned consumers and advocates working for quality long-term care nationwide. The site includes updates on residents' rights, quality of care and staffing, links to state

ombudsman, fact sheets, family involvement, and information on citizen advocacy groups. This site also contains action alerts regarding changes in federal, state, and local laws affecting care of the elderly.
National Center on Elder Abuse (NCEA) www.ncea.org - The National Center on Elder Abuse, directed by the U. S. Administration on Aging, is committed to helping national, state, and local partners in the field be fully prepared to ensure that older Americans will live with dignity, integrity, independence, and without abuse, neglect, and exploitation. The NCEA is a resource for policy makers, social service and health care practitioners, the justice system, researchers, advocates and families.It collects analyses national data on cases referred to and investigated by adult protective services, and serves as a resource to investigators worldwide.

National Committee for the Prevention of Elder Abuse (NCPEA)www.preventelderabuse.org. The NCPEA is an association of researchers, practitioners, educators, and advocates dedicated to protecting the safety, security and dignity of America's most vulnerable citizens.

National Family Caregivers Association (NFCA)www.thefamilycaregiver.orgThis site provides information about organizations providing caregiver support, tips for family caregivers, workshops and educational campaigns. NFCA offers free membership to any family caregiver. See the NFCA website for a list of volunteers in each state.
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