# Testimony of

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#### Before the:

# Senate Special Committee on Aging

hearing on
Justice for All: Ending Elder Abuse, Neglect and Financial Exploitation

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Chairman Kohl, Senator Corker, distinguished Committee members, thank you for inviting me to address the growing problem of elder abuse, neglect, and exploitation and for the Committee's long-standing bipartisan approach to and leadership on elder justice issues.

My name is Marie-Therese Connolly. I am a Senior Scholar at the Woodrow Wilson International Center for Scholars, and the Director of Life Long Justice, whose mission is to advance justice for older people by leveraging evidence, experience, expertise and evaluation. Life Long Justice is an initiative of and housed at the national headquarters of Appleseed, a nationwide network of justice centers that take a systemic approach to justice issues.

### I. THE PROBLEM

Last year, prosecutors in Seattle<sup>1</sup> charged Christopher Wise with the murder of his mother, Ruby. His crime? Letting her rot to death with eight huge pressure sores, several to the bone, while he played Internet poker and lived off her pension. His excuse? She didn't want to go to a nursing home or a doctor; he was just respecting her wishes.

Ruby Wise was imprisoned in her bed by immobility, dementia, and isolation. She moaned and cried out for help continuously in the weeks before her death. Neighbors closed their windows and her son put in earplugs to muffle her cries. No one called Adult Protective Services or 911. It's hard to believe the response would have been the same had the cries come from a child, a younger woman, or a dog.

The New York State prevalence data discussed by Dr. Lachs found that only one in 57 cases of

<sup>&</sup>lt;sup>1</sup> The King County Prosecutor's office in Seattle, Washington is a national leader in the prosecution of elder abuse, having created one of the first elder abuse units in the country. That Elder Abuse Unit is headed by Senior Prosecuting Attorney Page Ulrey, who also was the lead prosecutor on the Wise case.

elder neglect<sup>2</sup> ever comes to light. Ruby Wise's was one of the 56 that did not. Those 56 also will include people we love. We just may not know who yet.

#### A. How Extensive is Elder Abuse?

We'd like to think that what happened to Ruby Wise was a fluke. But it's not. A cluster of recent studies is beginning to give us a better handle on the prevalence of the problem among some parts of the older population. The New York State Elder Abuse Prevalence phone survey estimates that 7.6% of people over 60 have experienced elder abuse, neglect or financial exploitation in the past year.<sup>3</sup> A nationwide study using a similar random digit dialing methodology found a one year prevalence rate of about 10 percent for abuse and neglect.<sup>4</sup> The human toll these numbers represent is vast: 3.35 to 4.41 million of phone-answering, community dwelling Americans who passed a basic capacity screen have experienced some form of abuse, neglect or exploitation in the last year.

These recent prevalence studies allow us to isolate rates of financial exploitation. In the New York prevalence study, 41 per thousand surveyed self reported major financial exploitation (theft of money or property, using items without permission, impersonation to gain access, forcing or misleading to get items such as money, bank cards, accounts, power of attorney). Of those cases, only one in every 44 came to light.

But these phone surveys do not capture several populations at greatest risk: people who have dementia, live in facilities, can't answer or don't have a phone<sup>7</sup>, or those who are too scared to answer honestly or at all because an abuser is close by. People like Ruby Wise. In addition, such surveys do not reach the approximately 4.3 percent of people 55 and older who do not have either a land line or cell phone; or the uncalculated number who are not home or do not answer for other reasons.

People with dementia suffer staggering rates of mistreatment. A 2010 study by University of

<sup>&</sup>lt;sup>2</sup> The New York State Elder Abuse Prevalence study also found that only one in 44 cases of elder financial exploitation, one in 20 cases of physical and sexual abuse, and one in 12 cases of emotional abuse came to light. Overall, only one in every 23 cases of elder abuse, neglect or exploitation came to the attention of a responsible entity.

<sup>&</sup>lt;sup>3</sup> The New York State Elder Abuse Prevalence Study was conducted by a team of researchers from Weill Cornell Medical College, the New York City Department for the Aging, and Lifespan of Greater Rochester. The study targeted New Yorkers age 60+ who were able to participate in a phone survey and pass a basic dementia screen.

<sup>4</sup> Acierno, R., Hernandez-Tejada, M., Muzzy, W. & Steve, K. (2009) *Final Report: National Elder Mistreatment Study* (National Institute on Justice).

<sup>&</sup>lt;sup>5</sup> The New York State Elder Abuse Prevalence Study; Executive Summary, p. 3; this number is similar to the 5% one year prevalance rates found by Acierno et al. (witness' personal communication with researcher); see also Acierno, R, Hernandez, A, et al *Prevalence and Correlates of Emotional, Physical, Sexual and Financial Abue and Potential Neglect in the Unites States*: The National Elder Mistreatment Study, American Jounral of Public Health (Feb. 2010): 292-7; see also

<sup>&</sup>lt;sup>6</sup> The New York State Elder Abuse Prevalence Study; Executive Summary, p. 3; significant underreporting also MetLife Mature Market Institute, *Broken Trust: Elders, Family, and Finances*, 25 (March 2009) available at <a href="https://www.metlife.com/.../mmi-study-broken-trust-elders-family-finances.pdf">www.metlife.com/.../mmi-study-broken-trust-elders-family-finances.pdf</a>.

<sup>&</sup>lt;sup>7</sup> Household Telephone & Usage Patterns (2004) (4.3% of adults 55 and older have no land line or cell phone).

California, Irvine researchers found that 47% of people with dementia who were cared for at home by family members were mistreated. These findings are echoed in several other studies. Many of these studies find high rates of verbal, psychological or emotional abuse. Although physical abuse would seem to be more detrimental than verbal abuse, a 2010 Howard University study found that verbal abuse took an even worse toll on the mental health of women age 50-79 than physical abuse, indicating that we should take it just as seriously as other types of mistreatment.  $^{10}$ 

The phone surveys also do not include the approximately 2.5 million people<sup>11</sup> who live in facilities, and the prevalence of abuse, neglect, and exploitation in these settings is especially difficult to ascertain. But what we do know suggests cause for grave concern. In one study, nursing home staff interviewed about abuse reported that in the past year, 36% had seen at least one instance of physical abuse, 81% had seen at least one instance of psychological abuse, ten percent acknowledged they themselves had committed one or more physically abusive acts, and 40% reported committing one or more acts of psychological abuse.<sup>12</sup> Other studies involving interviews with nursing home staff revealed similar findings<sup>13</sup> and residents also report high

<sup>&</sup>lt;sup>8</sup> The breakdown among types of elder abuse is as follows: 10% by physical abuse, 14% by neglect, and 47% by psychological abuse. The numbers do not add up to 47% because some people suffered more than one type of mistreatment. In addition, the study did not include financial exploitation which likely would have driven the prevalence numbers even higher. Aileen Wiglesworth, Laura Mosqueda, Ruth Mulnard, Solomon Liao, Lisa Gibbs, William Fitzgerald, *Screening for Abuse and Neglect of People with Dementia*; Journal of the American Geriatrics Society, Vol. 58 Issue 3, March 11, 2010; <a href="http://www.centeronelderabuse.org/files/mp3/caregiving\_interview.mp3">http://www.centeronelderabuse.org/files/mp3/caregiving\_interview.mp3</a> (podcast discussing study).

Several international studies and one Florida study that similarly have found high prevalence rates (34 – 62%) of abuse among people with dementia living in home and community settings, *See* Cooney, C., Howard, R., & Lawlor, B. (2006). *Abuse of vulnerable people with dementia by their carers: Can we identify those most at risk?* International Journal of Geriatric Psychiatry, 21(6), 564-571. (52% overall, Physical abuse - 20%; Psychological abuse 42.5%; Neglect 4% -- N 82); Cooper, C., Selwood, A., Blanchard, M., Walker, Z., Blizard, R., & Livingston, G. (2009). *Abuse of people with dementia by family caregivers: Representative cross sectional survey.* British Medical Journal, 338(04/13), b155-7. (34% overall; Physical abuse - 4%; Psychological abuse 33%; N=220); VandeWeerd, C., & Paveza, G. J. (2005). *Verbal Mistreatment in Older Adults: A Look at Persons with Alzheimer's Disease and Their Caregivers in the State of Florida. Journal of Elder Abuse & Neglect, 17(4), 11-30;* (Psychological abuse only - 60.1% N=254); Yan, E., & Kwok, T. (2010), *Abuse of older Chinese with dementia by family caregivers: An inquiry into the role of caregiver burden.* International Journal of Geriatric Psychiatry, doi:10.1002/gps.2561; Overall - 62% (Physical abuse =18%; Psychological abuse=62%) N=122).

<sup>&</sup>lt;sup>10</sup> Mounton, C., *Psychosocial Effects of Physical and Verbal Abuse in Postmenopausal Women*, Annals of Family Medicine (2010); 8:206 – 213, *at* <u>www.annfammed.org/cgi/reprint/8/3/206.</u>

<sup>&</sup>lt;sup>11</sup> US Department of Health and Human Services, Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy, (2006), *The Size and Characteristics of the Residential Care Population: Evidence from Three National Surveys.* 

<sup>&</sup>lt;sup>12</sup> Pillemer, K. & Moore, David (1989). *Abuse of Patients in Nursing Homes: Findings from a Survey of Staff*, The Gerontologist 29 (3):314-320.

<sup>&</sup>lt;sup>13</sup> See, e.g., MacDonald, P. (2000). Make a Difference: Abuse/neglect Pilot Project. Danvers, MA: North Shore Elder Services. Project report to the National Citizens' Coalition for Nursing Home Reform, Washington, DC. In this study of 77 certified nursing assistants from 31 facilities, 58 percent of the CNAs said they had seen a staff member yell at a resident in anger; 36 percent had seen staff insult or swear at a resident; 11 percent had witnessed staff threatening to hit or throw something at a resident. These CNAs also reported that they had witnessed incidents of rough treatment and physical abuse of residents by other staff. Twenty-five percent of the CNAs witnessed staff isolating a resident beyond what was needed to manage his/her behavior; 21 percent witnessed restraint of a resident beyond what was needed; 11 percent saw a resident being denied food as punishment. In

levels of abuse and neglect. 14

National databases also provide evidence of significant abuse and neglect in nursing facilities, despite the \$144 billion in state and federal funding free-standing facilities received in 2009. In 2009, the On-line Survey, Certification and Reporting System (OSCAR) database free revealed that 16.78% of facilities were cited for abuse, improper use of chemical and physical restraints, and staff treatment of residents fraud almost a quarter of facilities received a citation for actual harm or placing residents in immediate jeopardy. However, studies by the Government Accountability Office (GAO) suggest that states consistently *understate* serious deficiencies.

It is also well documented that most nursing homes are understaffed at levels that cause harm to residents. <sup>20</sup> In 2009, a database of complaints received by Long-Term Care Ombudsmen revealed that "failure to respond to requests for assistance" was the most common complaint ombudsman staff received. <sup>21</sup>

addition, the staff reported witnessing more explicit instances of abuse. Twenty-one percent saw a resident pushed, grabbed, shoved, or pinched in anger; 12 percent witnessed staff slapping a resident; 7 percent saw a resident being kicked or hit with a fist; 3 percent saw staff throw something at a resident; and 1 percent saw a resident being hit with an object.

<sup>14</sup> In one study, 44% of residents interviewed by the Atlanta Long Term Care Ombudsman program reported that they had been abused and 38 percent of the residents reported that they had seen other residents being abused. Moreover, a striking 95% of residents interviewed in that study asserted that they had either been neglected themselves or witnessed other residents being neglected. One of the 80 residents who participated in the study reported: "I saw a nurse hit and yell at the lady across the hall because the nurse told the lady she didn't have all day to wait on her. The lady made some remark. The nurse hit the lady and said, 'Shut up.'"

The study also found that 48% of residents reported they had been treated roughly while 44% stated they had seen other residents being treated roughly. A resident reported: "My roommate—they throw him in the bed. They handle him any kind of way. He can't take up for himself." *The Silenced Voice Speaks Out: A Study of Abuse and Neglect of Nursing Home Residents*. Atlanta, GA: Atlanta Legal Aid Society and Washington, DC: National Citizens Coalition for Nursing Home Reform. (2000).

<sup>&</sup>lt;sup>15</sup> Harrington, C, Carillo, H, Blank, B.W., & Obrien, T, (2010), *Nursing Facilities, Staffing, Residents, and Facility Deficiencies*, 2004-2009, Dept. of Social and Behav'l Sciences, UCSF, available at: <a href="http://www.pascenter.org/documents/OSCAR\_complete\_2010.pdf">http://www.pascenter.org/documents/OSCAR\_complete\_2010.pdf</a>

<sup>&</sup>lt;sup>16</sup> The OSCAR system compiles information from state surveys of all 16,500 certified facilities in the United States in a uniform, computerized database.

<sup>&</sup>lt;sup>17</sup> Harrington, et al. (2010).

<sup>&</sup>lt;sup>18</sup> Harrington, et al. (2010).

<sup>&</sup>lt;sup>19</sup> See, GAO, Nursing Homes: Federal Monitoring Surveys Demonstrate Continued Understatement of Serious Care Problems and CMS Oversight Weaknesses, GAO-08-517 (Washington, D.C.: May 9, 2008) and GAO, Nursing Homes: Some Improvement Seen in Understatement of Serious Deficiencies, but Implications for the Longer-Term Trend Are Unclear, GAO-10-434R (Washington, D.C.: April 28, 2010).

Federal studies have demonstrated a direct relationship between low nursing home staffing levels and poor quality of care. *See, e.g.,* US Centers for Medicare and Medicaid Services, Prepared by Abt Associates Inc. *Appropriateness of Minimum Nurse Staffing Ratios in Nursing Homes. Report to Congress: Phase II Final. Volumes I-III.* Baltimore, MD: CMS, 2001 at 6-8.

<sup>&</sup>lt;sup>21</sup> In 2009, of 119 categories of nursing home complaints about which ombudsman collect data, "failure to respond to requests for assistance" was the single most frequent complaint and Ombudsman staff received 11,577 complaints of that nature. National Ombudsman Reporting System (2009), available

at http://www.aoa.gov/aoaroot/AoA Programs/Elder Rights/Ombudsman/National State Data/2008/Index.aspx.

Much less is known about non-nursing home residential care facilities (RCFs) that go by numerous names, including assisted living, board and care, congregate care, memory centers, or independent living facilities that also offer a la carte services. However, there is significant reason to be concerned about mistreatment.. Not only do we have substantial anecdotal evidence, but such facilities are increasingly catering to very fragile and vulnerable residents. Yet these facilities frequently lack the staff required to meet residents' needs, and, unlike nursing homes, are subject to uneven standards and vastly varied degrees of oversight. Since not all of these facilities are licensed in every state, some are not subject to any regulation at all and state authorities might not even be aware of their existence or the number of vulnerable elders who reside in them. A 2009 study found widespread breakdown in quality oversight systems governing such facilities and significant concerns about abuse and neglect.<sup>22</sup>

In hindsight, it's hard to know whether to believe Chris Wise's claim that his mother wanted to avoid going to a nursing home at all costs. <sup>23</sup> We know that abuse, neglect, and exploitation happen in every setting, from homes to nursing homes. Thus it is critical not only to establish a better understanding of prevalence rates in all settings, but also the relationship of prevalence in one setting to another. Developing a better understanding of the nature of this critical issue will help us to more effectively prevent and respond to it.

# B. Elder Abuse is on the Rise and We're Ill-Equipped to Address It

As 77 million baby boomers head inexorably toward old age, two populations at high risk for elder abuse also are among the fastest growing: people with dementia (already 5.3 million strong) and people 85+ (the fastest growing segment of the population, about half of whom have some degree of cognitive impairment<sup>24</sup>). The number of people who need long-term care is on a steady incline too.

But we have not figured out who will provide care for all who need it as the population ages. In addition to the approximately 2.5 million people who receive long term care in facilities, another 10 million receive it at home. <sup>25</sup> According to the Family Caregiver Association, 34 million

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<sup>&</sup>lt;sup>22</sup> Hawes, C & Kimball, A.M. (2009). *Detecting, Addressing, and Preventing Elder Abuse in Residential Care Facilities: Report to the National Institute of Justice.* 

Countless people do stay in risky, degrading and sometimes lethal situations just to stay out of a nursing home. In one New York study, 30% of seriously ill people said they'd rather die than go to a nursing home. Mattimore, T.J., et al., (1997), Surrogate and Physician Understanding of Patients' Preferences for Living Permanently in a Nursing Home, J. Am. Geriatr. Soc., Jul; 45(7), 818-24.

Agarwal, S. et al, *What is the Age of Reason?*, Center for Retirement Research at Boston College, July 2010, Number 10-12, citing lassman et al. (2007); Plassman et al. (2008);

Of those 10 million, about 800,000 depend exclusively on "formal caregivers" – paid or volunteer help associated with the health care or social service system. Family Caregiver Alliance, *Selected Long-Term Care Statistics*, at http://www.caregiver.org/caregiver/jsp/content\_node.jsp?nodeid=440.

<sup>1.4</sup> million people receive a combination of formal and informal care at home; and 7.8 million (78%) of the 10 million people receiving care at home depend exclusively on "informal caregivers" (also referred to as and usually in fact "family caregivers") – unpaid family, friends, neighbors and other community members who help out on a part or full time basis. The cumulative estimated economic value of informal care giving is \$257 billion a year.

people provide informal care for an adult age 50 or older, <sup>26</sup> and more will be called for service as the population ages. In addition, a generation of people with developmental disabilities, mental illness and substance abuse issues <sup>27</sup> who have relied on older relatives for care and support are, with the physical and cognitive decline of their older caregivers, being thrust into caregiving roles themselves, often beyond their capacity to deliver.

We have a long way to go to grapple with appropriate ways to prevent and identify elder abuse, especially that which occurs behind millions of closed doors. But if we're serious about wanting to "age in place," with dignity, decent care, self-determination, and without abuse or unnecessary suffering, we need to start devoting more brain-share to how to do so.

Not only are caregiver shortages growing, so are shortages of physicians and other medical professionals trained to navigate the vicissitudes of aging. Geriatricians don't do as many high priced and well-reimbursed procedures as other specialists, but their work has been shown<sup>28</sup> to decrease the need for home health care, enhance physical health and independence, and significantly reduce depression and disability. In other words, it reduces older people's risk factors for elder abuse. There's good anecdotal evidence to support the proposition that good geriatric care<sup>29</sup> reduces elder abuse.<sup>30</sup> That's significant given how little we know and do about prevention. Yet we have fewer than half the number of geriatricians we need to promote the kind of well-being we want in old age, and their numbers are going in the wrong direction – decreasing as our need sharply rises.

We have few programs in place to reach the Chris Wises of the world and prevent his mother's terrible suffering. But it's possible that had Ruby Wise been followed by one of the cutting edge geriatricians with a house call practice, that things may have turned out quite differently. Yet we lack research to demonstrate the link between house calls and prevention too. As elder abuse continues to rise, the paucity of prevention efforts will take an increasing toll, making it too a critical area for federal attention and leadership.

# C. The High Cost of Elder Abuse

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<sup>30</sup> Statements to the witness by geriatricians who are the leading national and international experts on elder abuse. Additional information available from the witness.

Of the 34 million informal caregivers, 8.9 million care for someone with dementia. Family Caregiver Alliance, Selected Long-Term Care Statistics, available athttp://www.caregiver.org/caregiver/jsp/content\_node.jsp?nodeid=440.

<sup>&</sup>lt;sup>27</sup> Substance abuse and mental illness among adult children caregivers appears to increase rates of elder abuse; *See* Schaimberg, Lawrence B. & Gans, Daphna (1999) *An Ecological Framework for Contextual Risk Factors in Elder Abuse by Adult Children*, Journal of Elder Abuse and Neglect, 11 (1), 79-103.

<sup>&</sup>lt;sup>28</sup> Atul Gawande, *The Way We Age Now*, The New Yorker (April 30, 2007), *available at*<a href="http://www.newyorker.com/reporting/2007/04/30/070430fa">http://www.newyorker.com/reporting/2007/04/30/070430fa</a> fact gawande. Boult C, Leff B, Boyd C, Wolff J,
Wegener S, Semanick L, Frey K, Rand-Giovannetti E. *A Cluster Randomized Controlled Trial of Guided Care:*<a href="Baseline Data and Initial Experiences">Baseline Data and Initial Experiences</a> J Am Geriatr Soc. 2007;55(4):S207. See also <sup>28</sup> See e.g. Mary Naylor, TITLE?,

Journal of American Geriatrics Society, May 2004, page numbers? This NIH study concluded that specialized nursing care for elderly heart patients results in better quality of life and fewer hospital readmissions. Instead of costing more money for specialized care, the care resulted in a nearly 38% savings in Medicare costs.

<sup>29</sup> The argument here is for garietiis ages delivered for the latest and the latest a

The argument here is for geriatric care delivered not only by physicians or geriatricians, but also by other health professionals, which also underscores the need for more and better geriatric training for all health professionals.

Statements to the witness by geriatricians who are the leading national and international experts on elder abuse

Victims of even mild elder abuse neglect or financial exploitation are at 300% increased risk of dying, compared to their non-abused contemporaries, in the three years after the mistreatment. 31 And the suffering elder abuse wreaks is not limited to the victims. It also exacts a terrible price from the people who love them, tearing apart families, squandering life savings, and undermining health, mental health, financial security and wellbeing in its wake, regardless of age.

Elder abuse often "tips over" the lives of its older victims, sending them cascading into a vortex of illness, suffering and expense borne by themselves, their families, and taxpayers.

People injured by physical abuse<sup>32</sup> often need expensive acute and long-term care, frequently financed by Medicare and Medicaid. Financial exploitation pushes victims who lose life savings to rely on public programs for housing and health care. Abusive guardianships squander court and administrative resources. And nursing home chains that neglect residents and bill for care they didn't provide defraud Medicare and Medicaid.

Child abuse is estimated to cost more than \$100 billion a year. 33 But we have not yet begun to assess the high cost of elder abuse, <sup>34</sup> even though we know that its price tag likely is many billions a year as well, given data relating to slices of the issue, including the following: that elder abuse leads to a four-fold increase in nursing home placement, 35 that understaffing in nursing homes leads to a 22% increase in avoidable hospitalizations, <sup>36</sup> that it leads to billions in

<sup>&</sup>lt;sup>31</sup> See Lachs et al., The Mortality of Elder Mistreatment, 280 JAMA 428, 428-32 (1999) (finding that victims even of mild abuse, neglect and exploitation were at 300% increased risk of death in the three years after the mistreatment compared to other elders, even adjusting for chronic illness and other factors.)

<sup>&</sup>lt;sup>32</sup> Bonnie Brandl, in her testimony before the Committee, refers to the plight of Miss Mary, a 96 year old Florida woman who was financially exploited and subsequently raped and physically assaulted by her drunk grandson with whom she lived. Although she lived independently before the attack, thereafter she was initially in a hospital followed by a nursing home, where she died a few years later. She never again lived independently. Miss Mary is an example of someone whose life was "tipped over," by abuse and the resulting care she needed was paid for by

public programs.

33 Foster, Michael and Holden, Wayne, *Benefit-cost analysis in the evaluation of child welfare programs*, Focus, Vol. 23, No. 1, Winter 2004; Wang, Ching-Tung, Holton, John, Total Estimated Cost of Child Abuse and Neglect in the United States, Economic Impact Study (September 2007), Prevent Child Abuse America; Prevent Child Abuse America, Total Estimated Cost of Child Abuse in the United States (2007) at http://member.preventchildabuse.org/site/PageServer?pagename=research\_child\_abuse.

<sup>34</sup> See Charmaine Spencer, Exploring the Social and Economic Costs of Abuse in Later Life, Gerontology Research Centre, Simon Fraser University, Vancouver, B.C., Canada. Prepared for Health Canada, Family Violence Prevention Unit, Ottawa, Ontario, Canada (1999) at http://129.3.20.41/eps/le/papers/0004/0004006.pdf. This was the only publication located discussing overall costs of elder abuse, neglect, and exploitation. The researcher is Canadian, much of the discussion applies to the United

<sup>&</sup>lt;sup>35</sup> Lachs, M, et al., *Adult Protective Service Use and Nursing Home Placement*, The Gerontologist (2002) 42 (6): 734-739 (finding that elder abuse almost quadruples nursing home placement).

<sup>&</sup>lt;sup>36</sup> Understaffing in nursing homes leads to a 22% increase in avoidable hospitalizations. Appropriateness of Minimum Nurse Staffing Ratios in Nursing Homes, Report to Congress prepared for the Centers for Medicare and Medicaid Services (CMS) by Abt Associates Inc., Andrew Kramer, University of Colorado Health Center on Aging and Division of Geriatric Medicine; et al. (Phase I report issued Summer 2000; Phase II, Final Report issued December 2001). These findings were consistent with those of a panel of the Institute of Medicine, National Research Council.

reported financial losses<sup>37</sup>; that it is less expensive to prevent (with specialized care) than to treat conditions associated with neglect and abuse, <sup>38</sup> such as injuries from falls, <sup>39</sup> dehydration, <sup>40</sup> and improper restraints; 41 and that it takes a reported

The many dimensions of the high cost of elder abuse thus present compelling moral, demographic, and fiscal imperatives to improve our response to this growing problem.

#### II. CHALLENGES IN ADDRESSING ELDER ABUSE

#### **Scant Research or Knowledge** A.

What we know about elder abuse lags some 40 years behind child abuse and 20 years behind domestic violence. We don't know why it occurs, how often it occurs among several populations, how much it costs, what practices and programs are most effective in addressing it, what the relationships are among its various forms, or how to detect and prevent it. We don't even know how to define what a successful intervention looks like. 42 Which is why we desperately need more research. And yet, according to the just released Government Accountability Office (GAO) report, in 2009, the National Institute on Aging (NIA), "leading the federal effort on aging research" spent just \$959,000, 1/1000 of its annual budget on elder abuse research; the Centers for Disease Control and Prevention (CDC) spent even less, (\$50,000); and the National Institute of Justice (NIJ) spent \$1.2 million; <sup>44</sup> for a grand total of \$2.2 million in federal dollars going to elder abuse research, a tiny fraction of what is spent on

<sup>37</sup> MetLife Mature Market Institute, *Broken Trust: Elders, Family, and Finances*, 8 (March 2009) available at www.metlife.com/.../mmi-study-broken-trust-elders-family-finances.pdf. (\$2.6 estimated losses due to financial exploitation as reported in media).

See e.g. Mary Naylor, Journal of American Geriatrics Society, May 2004, This NIH study concluded that specialized nursing care for elderly heart patients results in better quality of life and fewer hospital readmissions. Instead of costing more money for specialized care, the care resulted in a nearly 38% savings in Medicare costs.

National Center for Injury Prevention and Control, CDC, The cost of fall injuries among older adults, DATE? Online ref?. "The total cost of all fall injuries for people age 65 or older in 1994 was \$27.3 billion (Englander 1996). By 2020, the cost of fall injuries is expected to reach \$43.8 billion (in current dollars) (Englander 1996)." "A recent study of people aged 72 and older found that the average health care cost of a fall injury was \$19,440 (including hospital, nursing home, emergency room, and home health care, but not physician services) (Rizzo 1998)."

<sup>&</sup>lt;sup>40</sup> Preventing dehydration saves health care costs and improves quality of life. See, e.g., http://mga.dhs.state.tx.us/QMWeb/Dehydration.htm;

Phillips CD, Hawes C, Fries BE. Reducing the use of physical restraints in nursing homes: will it increase the costs? American Journal of Public Health. 1993; 83(3):342-48. Dunbar JM, Neufeld RR, Libow LS, Cohen CD, Foley WI. Taking charge: The role of nursing administrators in removing restraints. Journal of Nursing Administration. 1997; 27(3):42-48. Schnelle JF, Newman DR, White M, Volner TR, Burnett J, Cronqvist A, Ory M. Reducing and managing restraints in long term care facilities. Journal of the American Geriatrics Society. 1992; 40(4):381-85. Reducing the use of restraints in Texas Nursing Homes, Texas Department of Human Services in cooperation with the Texas Medical Directors Association and the Texas Medical Foundation.

<sup>&</sup>lt;sup>42</sup> We do have ideas and experiential knowledge regarding what we believe are successful interventions, but they are not yet evidence-based. Experiential knowledge has value but it would be hugely beneficial to conduct research on existing interventions and to develop innovative new interventions.

<sup>43</sup> http://www.nia.nih.gov/

<sup>44 \$650.000</sup> of the \$1.2 million came from DOJ's Elder Justice and Nursing Home Initiative housed in the Department's Civil Division. The EJI also funded other elder justice related activities in 2009 that did not appear in the GAO report because they related to facility issues beyond the purview of the GAO report.

## comparable issues.

One of the greatest research gaps in the field is that we know so little about the interventions we employ. APS plays a central role in elder abuse intervention. But we have not studied its efficacy. This would be no simple task due to the variance from state-to- state, region-to-region and law-to-law, not to mention diverse, and in some programs rudimentary, record keeping practices. But even beginning to study a few practices could provide critical information. This is not an insurmountable problem. But it is not one we have addressed with any real resources or methodological rigor.

Another issue regarding which there's a dearth of research is financial exploitation. Little is known (except anecdotally) about its nexus to other forms of elder abuse and neglect. There are a virtually limitless number of portals into the problem, ranging from legitimate entities and individual transactions that are misused to illicit ones that are in their nature designed to prey on older people. The decline in cognitive functioning that begins often in one's 50s, undermining capacity to make effective financial decisions also raises a plethora of policy dilemma raising to prevention that would benefit from elucidation. But often the complexity of the underlying financial transactions or rules require a degree of financial sophistication and training that most responders lack. And raising the question of how best to help people prepare for financial vulnerability and prevent becoming victims. Two recent surveys identify the reported rise in financial exploitation as a significant and growing concern for APS as well as other entities, and APS has cited it as a high priority issue on which it wants and would benefit from additional data. Another the complexity is a dearth of the reported research as a high priority issue on which it wants and would benefit from additional data.

The same dearth of efficacy data exists regarding the efforts of virtually all types of interveners including the Ombudsman, aging network entities, guardians, health care, legal and justice system personnel. Is there a difference in rates of elder abuse among patients cared for by geriatricians versus by physicians with less expertise in aging? (For example, poly-pharmacy or improperly diagnosed reversible delirium might lead elders to be at greater risk for abuse and neglect than they would have been with proper care.) Is there a difference in jurisdictions that have robust multidisciplinary teams? Are there better conditions in facilities that have a strong ombudsman programs or family councils? We also know little about whether and if so which interventions by police or prosecutors make elders safer. The domestic violence field has relied heavily on justice system interventions, including mandatory arrest, separating victims and perpetrators, and prosecution. It is unclear, however, to what extent those models make sense for the elder justice field.

Forensic research is another critical area. The jurors in the Ruby Wise case wanted to know how

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exploitation was the top subject on which APS administrators would like to see a demonstration project.)

<sup>&</sup>lt;sup>45</sup> Adult Protective Services: Increased Demand and Decreased Funds; AARP Public Policy Institue (2011) (Calls to APS, often attributed to rising financial exploitaiton, have incrased during the recession even as funding for the programs has remained the same or decreased.)

<sup>&</sup>lt;sup>46</sup> Strengthening Adult Protective Services (APS) and Informing Implementation of the Elder Justice Act: Nationwide Survey of APS Programs; Survey available at: www.appleseednetwork.org/LinkClick.aspx?fileticket=cuvxlBcxzwQ%3D&tabid=157 (reporting that financial

long her pressure sores had been there, whether they had occurred spontaneously or whether they had been caused by her son's neglect. Other than on the subject of bruising, we have little definitive forensic markers research to inform the answer to answer such questions.<sup>47</sup>

Section 2023 of the Elder Justice Act (EJA) requires the Department of Health and Human Services (HHS) to promulgate guidelines to the field regarding the navigation of human subject protection issue as they arise in elder abuse research. HHS guidance could make a significant difference as many Institutional Review Boards (IRBs) struggle to address such issues (often delaying research with time consuming analysis) because such research involves not one but two difficult issues – abuse and diminished capacity.

In addition, the EJA requires validated evaluation of the effectiveness of the activities funded under the Act. Particularly given the dearth of intervention research and the need to assure that scarce resources are used most effectively, the field would benefit from HHS guidance regarding how to structure such evaluations.

## B. Complexity

Elder abuse is comprised of a constellation of distinct but related phenomena that implicate health, social service, legal, financial and other systems. The issues raised in this hearing illustrate the problem's breadth – financial exploitation, withholding of critical necessities, neglect, and physical and sexual assault. Elder abuse emerges in all kinds of settings and involves an unwieldy panoply of players and systems. As such, it also requires a multi-faceted response from the federal government and otherwise.

One of the most fundamental complexities in the field is finding the right balance in our response to elder abuse between self-determination on the one hand, and safety on the other. The autonomy-safety conundrum plays out in the individual, programmatic, systems, medical, legal, and policy realms. Striking the right balance is a constant challenge for responders, family members, government officials, researchers and policy makers in addressing decisions about living at home alone, refusing needed care, spending/squandering money, engaging in physical intimacy, staying with an abuser or neglecter, hoarding, living in squalor, and more. Responders are whipsawed by vague or conflicting demands of family members, professional rules, philosophy, a haphazard system of laws, ethical guidelines, and their own consciences.

Elder abuse consists of numerous different types of abuse. It could be a confused older man at the bank being targeted for financial exploitation. It could be a demented nursing home resident neglected and unfed. It could be someone cognitively and physically able, victimized by

<sup>&</sup>lt;sup>47</sup> See e.g., Laura Mosqueda, Kerry Burnight, & Solomon Liao, *The Lifecycle of Bruises in Older Adults*, 53 J. AM. GERIATRICS SOC'Y 1339 (2005); Wiglesworth A, Austin R, Corona M, Schneider D, Liao S, Gibbs L, Mosqueda L. Bruising as a marker of physical elder abuse. *Journal of American Geriatrics Society*, 2009 Jul;57(7):1191-6, at <a href="http://www.centeronelderabuse.org/research.asp">http://www.centeronelderabuse.org/research.asp</a>. See also, "A Multi-Site Study to Characterize Pressure Ulcers in Long-Term Care Under Best Practices: Final Technical Report for the U.S. Justice Department," Liao S, Baker M, Lowe J, Austin '?R, Whitney JD, Wiglesworth A, Zimmerman D, Zoromski P, Mosqueda L

domestic violence in later life. These different phenomena represent just a small fraction of the many faces of elder abuse. Victim populations too span a broad range (e.g. people with cognitive impairment and those who are cognitively intact) requiring different services and intervention responses. And perpetrators can be power hungry and bullying, incompetent and well-meaning, or take the inanimate form of a financial institution or a care facility. In other words, elder abuse is a phenomenally heterogeneous problem where one size never fits all.

In addition, we know little about the causes of elder abuse. We lack validated theoretical models to explain why elder abuse occurs and to inform our responses in individual cases and at a policy level. For example, applying a "power and control" model used in the domestic violence field leads to different types of interventions and policies than a "caregiver stress" model, with potential implications for victim safety and well being. A "caregiver stress" model suggests the perpetrator needs assistance. Under a "power and control" model, however, the perpetrator more likely would be separated from the victim – two very different responses. Thus, it is vital that we advance our understanding of why elder abuse occurs to get a better handle on what interventions are most likely to work. Given the complex constellation of phenomena that make up the problem, it is likely that several theoretical models and frameworks will apply, depending, for example, on whether the victim and/or the perpetrator have capacity or money is a motivating factor.

There is little research or training for those on the front lines, such as Adult Protective Services (APS), law enforcement and EMS, about how to ascertain "consent" with persons who have somewhat diminished capacity. When should they adhere to the older person's preferences and when should they consider potentially conflicting opinions of another family member; and how to determine what is truly in their client/beneficiary/patient/victim/resident/subject/mom's "best interest." We don't even know how to define a "successful" outcome. Had APS been called, and Ruby Wise moved from her home into a nursing home, would that have been a successful outcome? Perhaps if her suffering had been reduced?

Yet another related complexity that deserves be systematically analyzed and addressed at the national level is the paucity of "good options." First responders such as APS, medical personnel, EMS, law enforcement, and others, often do not have available to them remedies that that victims (or individuals at risk) want or would accept. This scenario arises, for example, with aging parents who for decades have cared for mentally ill or developmentally disabled now-adult-children. As their physical and cognitive capacity declines, they grow increasingly dependent on the offspring. The parents may be adamant that they understand the risk but do not want to be separated from their children who lack the capacity to provide the care they need — which can be a recipe for disaster. Most communities and responders lack access to placement options where both parent and child can go together and have their divergent needs met, or source of funds to allow them to procure in-home care.

We need more data about what remedies older victims and people at risk need and want most, whether it is possible to make those options available within the structure of existing laws and programs, or whether something new is required. In addition, responders often need more information about the range of services available to elder abuse victims and those intervening on their behalf, including in response to financial exploitation.

We thus need an analysis about what services *should* be minimally available in all localities; what services *are* currently available in different localities; what information about those services is available to victims, those at risk, and those intervening on their behalf; and what ethical guidelines are available to families and responders to guide them in navigating these often complex and murky waters.

## C. Fragmented Systems and Service Shortages

The response to elder abuse (when cases come to light, which most do not<sup>48</sup>) is hampered not only by too few resources, but also by a fragmented patchwork of systems, programs, laws, philosophies, practices, and jury-rigged responses. The safety net, to the extent it exists, is full of holes and looks different in every jurisdiction. The Elder Abuse Victims Act study of laws and creation of and support for multidisciplinary task forces would begin to address this issue.

APS, which exists in every state as a protective services entity, is charged with responding to and investigating allegations of elder abuse. <sup>49</sup> On the local level, APS cases require medical, legal, and financial expertise that is often not available to APS staff and services that APS clients frequently cannot access. Some APS programs have developed partnerships and are part of multi-disciplinary teams but other programs are able to offer only limited assistance to victims even once they suspect or substantiate abuse, neglect, or exploitation. The GAO report and the testimony of Kathleen Quinn, Executive Director of the National Adult Protective Services Association, have illustrated that the dramatic shortfall in resources at the state level is exacerbated by the lack of federal standards, training, technical support, data collection, oversight or infrastructure, such as an office or resource center. This high level national support is of the type that the federal government already provides for many other systems and could be provided for APS with relatively modest resources. <sup>50</sup>

In a few jurisdictions, law enforcement or prosecutors prefer to conduct the initial investigation into an alleged elder abuse case before APS. In other jurisdictions, where the justice system is less engaged, APS may try to develop a more thorough investigation to build a case that law enforcement might pursue. APS has authority to go into long term care facilities in about half of the states but the lines between APS's role in those states and the role of the state licensing

www.appleseednetwork.org/LinkClick.aspx?fileticket=cuvxlBcxzwQ%3D&tabid=157.)

<sup>&</sup>lt;sup>48</sup> See discussion above about the New York State Prevalence study's findings regarding the vast majority of cases not coming to light.

<sup>&</sup>lt;sup>49</sup> In some states, such as New York, the aging network pursues cases that fall outside of APS' eligibility criteria.

Life Long Justice conducted a survey of APS programs with the assistance of volunteers and the pro bono assistance of Edgeworth Economics. The survey revealed a consistent refrain of the dire need for funding and more staff. In addition, the three top subjects on which APS programs would like to see a demonstration project funded, are financial exploitation, collaboration with law enforcement and others, and measuring effectiveness of their interventions. Survey participants identified their top two legal or policy challenges as being guardianship and the need to standardize, update, and consolidate laws and policies. In addition, the APS administrators had many pressing requests for support from a national resource center or similar support vehicle including developing best practices, increasing public awareness, providing input regarding APS into law reform and policy development, coordinating initiatives with critical partners and compiling APS data, disseminating research findings and developing national training. (Survey available at:

agency and the long term care ombudsman program are sometimes blurry. For example, in at least two states, alleged wrongdoing by a staff member or another resident of a residential care facility is under the purview of the agency that licenses facilities, whereas the same conduct perpetrated by someone coming in from the outside would go to APS. <sup>51</sup>

Like APS, most victim assistance, services or advocacy programs on the front line responding to allegations of elder abuse report difficulty in finding appropriate (or any) victim services for elder abuse victims (who often have complex medical, mental health, legal, financial, and/or housing needs). While a few programs focused on elder abuse victims offer space in domestic violence shelters, transitional housing, or emergency nursing home placement, and some prosecutors and law enforcement offices have elder victim assistance personnel, little is known about how best to meet the housing and other needs of older victims. The proposed Elder Abuse Victims Act would bring much-needed attention to address this victim assistance gap.

In addition, many if not most elder abuse cases involve a mental health issue relating to the victim, the perpetrator, or both. Mental health systems are not well meshed with the elder abuse network, such as it is, and there is less awareness than there needs to be about the mental health issues of older adults and the nexus between mental health issues and elder abuse.

Similarly, financial issues and systems are increasingly implicated in elder abuse cases, thus requiring those in the elder justice field to develop new familiarity with that system and requiring of various representatives of financial institutions a crash course in elder abuse. In addition, financial institutions and experts have become more common participants in multidisciplinary teams and taskforces.

Research exists indicating that identifying perpetrator<sup>52</sup> characteristics and typologies<sup>53</sup> is more important to preventing elder abuse than identifying victim characteristics.<sup>54</sup> But we have few services to address those troubling characteristics. We need much more wide-ranging studies so that we know who abuses, who neglects, who exploits and what interventions prevent or stop such mistreatment.

Some programs that provide direct services to victims, such as APS, ombudsman programs, and legal services, are housed in and/or funded by State Units on Aging and Area Agencies on Aging. Advocates working in those programs may sometimes feel conflicts between the systemic advocacy they believe is necessary to address the unmet needs of elder abuse victims and pressure from their funders to stifle any criticism of local or state agencies and programs. These conflicts can be yet another barrier for individuals who are most familiar with the needs of

<sup>&</sup>lt;sup>51</sup>Both Washington and Michigan divide responsibilities in this way.

<sup>&</sup>lt;sup>52</sup> A "perpetrator" might include a range of individuals and/or entities whose actions or omissions may result in abuse, neglect or exploitation of elders. We lack data about *all* types of potential perpetrators: (a) individuals, (b) groups (families or informal groups, such as Roma-Gypsies who prey on older people), or (c) corporate entities (a nursing home chain where profits trump care needs, or boiler room operations dialing for dollars).

<sup>&</sup>lt;sup>53</sup> Holly Ramsey-Klawsnick, *Elder-Abuse Offenders: A Typology* 24 GENERATIONS (2000).

<sup>&</sup>lt;sup>54</sup> GEORGIA ANETZBERGER, THE ETIOLOGY OF ELDER ABUSE BY ADULT OFFSPRING (1987).

victims and the shortcomings of the system to raise and address those issues in meaningful and effective ways.

These many fragmented systems would benefit from systemic evaluation and identification of workable models and practices. Multidisciplinary taskforces<sup>55</sup> addressing elder abuse, including those envisioned in the Elder Abuse Victims Act, could assist in addressing the problem of fragmented systems and assure that the lessons they have learned are made available for other jurisdictions and entities facing the same challenges.

## D. The Urgent Need for Elder Justice Appropriations

Congress has yet to appropriate a single cent to implement the Elder Justice Act enacted in 2010 or the 2006 elder justice amendments to the Older Americans Act. And it has appropriated only modest funds (\$5.9 million) to implement the remaining OAA provisions that would address elder abuse (and has left several provisions unfunded for decades). Fully funding the modest amounts authorized in those federal elder justice laws is among the most significant needs in the field. The oral testimony from the witnesses, as well as the written testimony from myriad entities and individuals submitted into the record, illustrate countless manifestations of the dire need for funding. The GAO's report (and the pie charts attached as Exhibit A) illustrating the GAO's findings regarding federal expenditures illustrate just how meager the federal resources are compared to the great and growing need.

# E. Elder Justice is Not a Federal Priority – Yet

The Department of Justice (DOJ) and the Department of Health and Human Services (HHS) have for years had offices that have provided sustained leadership, attention and activity relating to child abuse and domestic violence issues. No similar office exists to address elder abuse. The result of this lack of sustained leadership, infrastructure and resources that such an office would bring are evident in the GAO report of March 2, 2011, *Stronger Federal Leadership could Enhance National Response to Elder Abuse*, and in the charts illustrating the GAO findings (Exhibit A).

The federal effort on elder justice is minimal – according to GAO it was \$11.7 million in 2009 – and a fraction of that devoted to address child abuse and domestic violence. The irony of this deficit is starkest at the two federal entities whose missions explicitly relate to aging: As noted above in the research section, the National Institute on Aging spent just \$959,000 (0.1%) of its budget on elder abuse research (in both 2008 and 2009). According to the GAO, the Administration on Aging spent about \$5.9 million (0.4% of its 2009 budget) on elder abuse research. <sup>56</sup>

funded under the elder abuse program in the Vioence Agaisnt Women Act.

56 AoA also spent \$16 million on the Long Term Care Ombudsman. GAO did not measure the federal effort or

<sup>&</sup>lt;sup>55</sup> One model for such task forces to examine are the coordinated community response (CCR) teams currently funded under the elder abuse program in the Vioence Agaisnt Women Act.

AoA also spent \$16 million on the Long Term Care Ombudsman. GAO did not measure the federal effort or amounts expended on abuse and neglect in facilities and thus did not analyze amounts spent by the Centers for Medicare and Medicaid Services (CMS) on efforts to address elder abuse.

In addition, the Centers for Disease Control and Prevention spent just \$50,000 (0.0008%) of its budget on elder abuse issues (\$5,000 less than in the previous year) whereas it has for decades spent millions and provided real leadership on issues relating to child abuse and domestic violence. 57 Moreover, Adult Protective Services, a critical front line responder to elder abuse, does not have a federal office, resource center, standards, oversight, training, data collection or reliable funding.

The scenario is similar at DOJ: Although the aging population is disproportionately female, people who have dementia are disproportionately women, elder abuse victims are disproportionately women, recent research indicates that among phone survey respondents who have capacity, much of the elder abuse is domestic violence, 58 and despite the rapidly aging population, the Office on Violence Against Women (OVW) spent only 0.5% of st its funds on elder abuse. APS programs and others working on the front lines of elder abuse and some researchers report that few domestic violence or sexual assault programs <sup>60</sup> serve older victims on the basis of age, disability or both. Either category is suspect, particularly for a recipient of federal funds.

Similarly, the GAO reports that the Office of Justice Programs (OJP), DOJ's grant-making arm, in FY 2009 spent just over \$1 million of its own budget to address elder abuse. 61 Two OJP bureaus that have been involved in elder justice projects are not shown by the GAO's analysis as having been so in 2009.<sup>62</sup>

expended \$516,000 on elder abuse projects in 2009.

 $<sup>^{57}</sup>$  The CDC has initiated an effort to identify definitions of elder abuse for purposes of surveillance. It is critical that such an effort be coordinated with other federal entities and the definitions used by leading programs and practitioners in the field. There has been recent movement in the field about new ways to conceptualize the problem and questions about whether relationships with "an expectation of trust" should be a threshold requirement for any case of elder abuse (which would leave out certain types of abuse targeting an older person based on age, but leave in abuse that occurs regardless of age.). See for example the definitions used by the New York City Elder Abuse Center and the University of California, Irvine Center of Excellence and the Orange County Elder Abuse Forensic Center and the Canadian work regarding elder abuse definitions.

<sup>&</sup>lt;sup>58</sup> Ron Acierno, Melba Hernandez-Tejada, Wendy Muzzy, & Kenneth Steve, *National Elder Mistreatment Study*, (March 2009).

<sup>&</sup>lt;sup>59</sup> The funds expended under VAWA annually to addres elder abue primarily go to elder abuse coordinated community response teams now in existence in many jurisdictions, which have been successful in bringing many new systems and individuals into the elder jsutice field.

<sup>&</sup>lt;sup>60</sup> Vinton, Linda. (1998) A Nationwide Survey of DV Shelters' Programming for Older Women. Violence Against Women, 4(5) 559-571; and cf, Meeting Survivors' Needs: A Multi-State Study of DV Shelter; Experiences Eleanor Lyon, Shannon Lane, Anne Menard (2008) DOJ award; 2007-IJ-CX-K022. Doc #: 226045.; Marta Lundy and Susan Grossman "Elder Abuse: Spouse/Intimate Partner Abuse and Family Violence Among Elders; JEAN 16(1) 2004. 85 – 102; Vinton, Linda. (1998) A Nationwide Survey of DV Shelters' Programming for Older Women. Violence Against Women, 4(5) 559-571. Statements by APS program administrators and others to the witness The GAO report notes that \$650,000 of the \$1.2 million expended by NIJ on elder abuse was contributed by the Elder Justice and Nursing Home Initiative. In addition to the NIJ research grant program (the first and still only sustained federal elder justice research grant program), the GAO reports that the Office for Victims of Crime

<sup>&</sup>lt;sup>62</sup> The GAO report showed no funds being spent on elder abuse by the Office of Justice Program's (OJP's) bureaus that address elder abuse data and justice program, both of which are much needed and have much to contribute:..

Bureau of Justice Statistics (BJS) that supports law enforcement, courts, corrections, treatment, victim services, technology, and prevention to strengthen the criminal justice system, and

DOJ's Office for Victims of Crime (OVC) primarily distributes fund to the states through formula grants for direct victim assistance (such as rape crisis centers, domestic violence shelters, and victim advocates in prosecutors' offices) and victim compensation programs (to reimburse victims for their mental health, health care, and burial service expenses). This accounts for the lion's share of OVC funds. It appears that a total of 127,426 victims of elder abuse were served in FY2007 and 2008 by Victim of Crime Act (VOCA) Assistance Programs or 2% of all victims served by these programs. <sup>63</sup> Of OVC's 2009 discretionary funds, only \$516,000 were expended on elder abuse efforts.

If you fund them, they will come. When promising young researchers make decisions about their fields of work, one factor they must consider is the availability of funding. A small number of researchers have obtained funding for elder abuse research. But in general, the eye of the needle is very small, and elder abuse research is not now considered to be a promising field given the dearth of funds that flow to it. Thus, those putative promising young researchers likely will preemptively pursue other areas of practice where they are more likely to be able to do the work they aspire to. And thus, the cycle perpetuates itself.

Overall, federal elder justice efforts are pursued by a few dedicated officials, who usually juggle elder justice efforts with multiple other duties. Although the issue has been referred to by HHS Assistant Secretary for Aging Kathy Greenlee as "the growing crisis of elder abuse, <sup>64</sup> and she has designated it as one of her highest priorities, AoA has received no funds (either appropriated by Congress or discretionary sums allocated by the Administration) with which to implement the Elder Justice Act (2010) or the 2006 elder justice provisions of the Older Americans Act. And the modest \$5.9 million Congress appropriated for AoA to implement the pre-2006 elder abuse-related provisions of the OAA, is not enough to have any significant impact given the vastness and complexity of the problem and the fragmented state of the response.

The same scenario is replicated at the Department of Justice where elder justice efforts enjoy support at high levels of the Office of Justice Programs and the Civil Division, but receive just a tiny fraction of the funding that goes to comparable issues. Nor has elder justice ever managed to draw an influential champion in the White House to assure attention and funding.

In sum, elder justice has never been assigned true priority on the national agenda with resources to match. And the fall out from this deficit are evident everywhere.

### III. THE ROAD FORWARD

# A. Infrastructure and Sustained Attention

<sup>•</sup> Bureau of Justice Statistics (BJS) the mission of which is to collect, analyze, publish, and disseminate information on crime, criminal offenders, victims of crime, and the operation of justice systems.

<sup>63</sup> http://www.ovc.gov/welcovc/reporttonation2009/ReporttoNation09full.pdf)

<sup>&</sup>lt;sup>64</sup> Testimony of Kathy Greenlee, Assistant Secretary for Aging, U.S. Department of Health and Human Services, before the Senate Special Committee on Aging; Field Hearing on Reauthorization of the Older Americans Act; September 7, 2010; Milwaukee, Wisconsin, p. 4.

Federal leadership and infrastructure can have a tremendous impact on how a country addresses a problem, on whether it gets the attention it needs and deserves. Such leadership begins with the bully pulpit to make public the priority and thereby validate it and raise awareness about its existence and importance.

The new office proposed for DOJ is a low-cost, potentially high-impact measure that could concentrate and focus the federal effort, provide sustained policy and program development, and be the focal point to assist, coordinate and support the work done by the state multidisciplinary taskforces (also envisioned in the bill). The lessons learned by those task forces would not remain the sole province of that task force or locale, but could instead be analyzed and disseminated nationally for the benefit of other states and taskforces across the country.

In addition, the office could, in coordination with other federal offices and agencies, assure methodologically appropriate evaluation of efforts undertaken under its auspices, to begin addressing the deficit of knowledge about which efforts best advance the wellbeing of the population we seek to serve. Such ongoing emphasis on evaluation could make a significant contribution to the field.

The Elder Abuse Victims Act also calls for the DOJ Office of Elder Justice to conduct a review of state laws used in elder abuse cases and of practices relating to the enforcement of those laws. Given the patchwork of different types of laws used in civil, criminal and injunctive elder abuse cases, such a review is much needed.

In the death of his mother, Chris Wise was acquitted of both murder in the second degree and acquitted of manslaughter in the first degree. He was convicted of manslaughter in the second degree, which does not require a showing of recklessness. Had he been charged with knowingly and recklessly causing egregious suffering (instead of causing death), the jury likely would have convicted. But, as one juror pointed out, the law did not fit the crime very well. This is not an infrequent issue in elder abuse cases —laws often do not fit the wrongs they're being used to redress. For one state to have ready access to the text and experience of others will be of significant benefit to the field.

The review of state laws also should include an analytic component, a review of how those laws have been enforced and the state's experience with it. Such an analysis will be particularly helpful to states trying to determine what kinds of laws and enforcement practices make the most sense. In addition, two recent compendia of federal laws relating to elder justice will fill out the federal aspects of the legal landscape, the Congressional Research Service's *Compendium of Statutory Authorities the Address Prevention, Detection or Treatment of Elder Abuse*, <sup>65</sup> and Life Long Justice's *Elder Justice Legislative Map* <sup>66</sup>.

The legislative map is a working resource document that currently includes the Elder Justice Act, the elder justice provisions of the Older Americans Act, and the elder abuse provisions of the Violence Against Women Act. It allows users to use hyperlinks to examine related documents and to sort the laws' sections by categories such as research, services, training, appropriations, and more. The EJ Legislative Map was prepared by a team of *pro bono* 

<sup>&</sup>lt;sup>65</sup> This compendium was done for the Senate Special Committee on Aging and covers numerous federal laws.

#### **B.** Data Collection

#### Elder Abuse Data Collection

The child abuse field has for decades collected extensive data relating to child abuse. The elder abuse field has not begun to do so. This despite the fact that such data collection has been identified as an urgent priority for years and despite the fact that it was mandated by the 2006 amendments to the Older Americans Act. The GAO notes that AoA has not fulfilled the OAA's requirement to develop objectives and priorities for the long term planning to collect uniform national data about elder abuse, <sup>67</sup> and recommends that HHS together with DOJ, state representatives, and relevant experts work together on this issue.

We have sufficient preliminary information today to begin laying the foundation for collecting uniform national data regarding elder abuse. The March 2010 *Congressional Report on the Feasibility of Establishing a Uniform National Database on Elder Abuse* provides a significant preliminary analysis to assist and inform such a process. The next step is for HHS and DOJ to convene a working group of experts on data, elder abuse, state data collection systems, child abuse and domestic violence data collection, and others necessary and helpful to the process, to begin developing a plan.

The child abuse field pursued a two-year design phase, held two large regional meetings which most states attended, scoped the system and got agreement about the big issues. People involved in the process report that the states too were also eager also to have better data to more effectively address the issue.

A key ingredient? A consistent champion inside the federal government. Such a program must have continuing support and focus. In this case we need champions inside both DOJ and HHS who can and will work together and with an assembled team.

#### APS Data Collection

In addition to collecting field-wide data, GAO also recommends collection of APS-related data as required by the Elder Justice Act. It will be critical that these two data collection processes (field wide and APS only) coordinate and are linked so that they complement as opposed to undermine one another.

Appleseed's Life Long Justice initiative recently conducted a state-by-state survey of APS programs to collect data relevant to and to inform the early stages of collecting APS data. The findings of that survey have laid some initial groundwork.<sup>68</sup> Notably, categories about which

attorneys at Hogan Lovells for and in consultation with Appleseed's Life Long Justice program, and will be available on the Life Long Justice website,

www.appleseednetwork.org/bOurProjectsb/LifeLongJustice/tabid/594/Default.aspx#legislation.

<sup>&</sup>lt;sup>67</sup> Following up on the discussion above in I(A) regarding prevalence, it is critical in this effort to assure that elder abuse in all settings and among all populations is considered in determining what data to collect.

See survey at online at <a href="https://www.appleseednetwork.org/LinkClick.aspx?fileticket=cuvxlBcxzwQ%3D&tabid=157">www.appleseednetwork.org/LinkClick.aspx?fileticket=cuvxlBcxzwQ%3D&tabid=157</a>);

APS programs collected the least data – client's and perpetrators' capacity – may be among the data points with the greatest potential correlation to risk for elder abuse. In addition few programs collect information about the reasons *why* reports were not substantiated, which may be among the more useful types of information in identifying challenges.

Perhaps the most significant survey finding came in response to a question relating to how APS programs measure program effectiveness. There was no consistent or meaningful definition of "success." And although just under half of the programs collect data about "client outcomes," it is not clear how "outcome" is defined, whose outcome it is, and whether the clients would rate those "outcomes" the same as APS. It is notable that, as noted above in note 43, among the top three choices of topics to pursue in a demonstration project was "measuring effectiveness and outcomes..."

## C. Implementation of Existing Laws

While the failure of Congress to appropriate funds to implement the federal law relating to elder justice, is an enormous barrier to progress in this field, not all aspects of implementation must rise and fall with appropriations. First, the administration can make choices regarding where and how to spend its discretionary dollars and would make a statement about the importance of addressing elder abuse by using some available sums to address the most pressing needs of the field. Second, part of demonstrating visible leadership on elder justice issues, and conveying that they have some priority, includes using the bully pulpit and taking visible steps to plan for implementation, similar to what has occurred relating to other laws.

One possibility would be for the federal agencies to convene or seek the input of multidisciplinary groups of experts regarding recommendations for the most effective implementation of those elder justice-related laws.

More than 90% of programs collect information about the client's gender and age; more than 80% about setting and where the abuse occurred. But just over 50% collect information about client's functional capacity (such as ADLs) and cognitive capacity. As discussed above, there are persuasive data that individuals with dementia are at much higher risk for elder abuse; and there is research underway indicating that individuals with diminished functional capacity also are at greater risk. Thus, currently, just over half of programs collect the client information most closely correlated with likelihood of abuse.

The same is true for perpetrator data. Whereas 89% of programs collect information about perpetrator relationship to client, 69% collect data about perpetrator gender, and 45% collect data about perpetrator age, only 21% collect information about perpetrators' cognitive capacity. And yet some studies indicate a correlation between substance abuse, mental illness and increased rates of perpetrating elder abuse, making cognitive capacity a compelling factor to pursue, in addition to substance abuse and mental illness.

APS programs also indicated what factors would make it more feasible for them to collect or retrieve data, which will be relevant data as decisions are made regarding where to put funds.

<sup>69</sup> Schaimberg, Lawrence B & Gans, Daphna (1999); *An Ecological Framework for Contextual Risk Factors in Elder Abuse by Adult Children*; Journal of Elder Abuse and Neglect, 11 (1), 79 – 103.

<sup>70</sup> 60% of programs collected information about repeat referral rates or recidivism; 48% "client outcomes," 35% collect "risk reduction" data, and 14% collect information about arrest and prosecution data.

<sup>71</sup> For example, the Section 1150B's require reporting of crimes that occur in federally funded long term facilities to nursing homes is already in force and the field could use guidance regarding its implementation. In addition, it would seem that at least some aspects of implementing the Coordinating Council (Section 2021), Research Protections (Section 2023), provisions could proceed absent appropriations.

## D. A Strategic Elder Justice Plan

The dearth of funding notwithstanding, there is commitment to basic principle of elder justice among a handful of dedicated career and political appointees in the executive branch. These federal employees could do much to advance the field by developing a collaborative, public-private, federal-state-local strategic plan for establishing a lasting place for elder justice issues, and setting some reachable priorities could do much to advance the field.

There are several potential vehicles for the development of such a plan. The Coordinating Council could take a visible leadership role, involve others in this effort, and create a timeline that will assure sustained attention to this issue. The Elder Justice Roadmap Project, <sup>72</sup> co-funded by DOJ and HHS, could be a vehicle to contribute substantive input from the field to inform such a strategic plan. Once elder justice is seen as a prominent concern on the federal agenda, new voices will begin to speak to and about the issue, including other potential funders who have had little involvement in elder justice issues (but who watch attentively to issues of concern to the administration; where the federal government leads, funders often follow, to issues perceived to have priority and traction).

#### **CONCLUSION**

With 77 million baby boomers aging, dementia on the rise, and caregiver shortages looming, experts agree that "the growing crisis of elder abuse" has significant implications for the health, well-being and economic security of millions of Americans.

Elder abuse is not just an aging issue. It's a baby boomer issue too, for the millions of people struggling to promote the safety and well being of both their parents and their children. By not meaningfully acknowledging, let alone addressing elder abuse, we are sending an insidious message that suffering in old age is somehow less worthy of our best effort.

The looming implications of elder abuse should be part of our national conversations about health care, justice, economic reform, protecting Medicare and Medicaid from waste, fraud and abuse, government efficiency, and the nexus between responder and caregiver shortages and creating new jobs.

Mickey Rooney has vividly illustrated that elder abuse can arrive unannounced and unbidden at anyone's door – his, our grandparents,' our parents,' or our own. Awareness is the first step toward prevention. We thus owe him a great debt of gratitude for having come forward to

<sup>&</sup>lt;sup>72</sup> The recently launched Elder Justice Roadmap Project, funded by DOJ's Elder Justice Initiative in collaboration with AoA and the Assistant Secretary for Planning and Evaluation, (ASPE), involves soliciting views from hundreds of stakeholders to identify and distill priorities for research, policy and practice as they relates to elder abuse, neglect and exploitation. The ensuing roadmap with its priorities could provide much needed strategic direction and informed priorities for the field.

discuss his personal experience.

We've spent countless billions to extend how *long* we live, but relatively little to assure dignity and well-being in the years we've gained. Like Chris Wise, we as a nation also have been wearing earplugs. It is time that we remove them.

Elder justice is a justice issue for our age.

Thank you.