



**NATIONAL COMMITTEE
FOR THE PREVENTION OF ELDER ABUSE**

Symposium on Self- Neglect

Building a Coordinated Response

A Report of the Education Committee

February 2008

Executive Summary

Although self-neglect comprises the largest category of cases served by adult protective service (APS) programs, its inclusion in the lexicon of elder abuse has been a subject of heated debate over the last half-century. The National Committee for the Prevention of Elder Abuse self-neglect symposium, the first of its kind in the United States, brought together researchers, policy makers, educators and practitioners from around the United States to identify key issues surrounding self-neglect and to make recommendations for actions needed to create a coordinated interdisciplinary approach to the problem. Addressing self-neglect is complicated by opposing ethical principles: the duty of society to protect versus the individual right to self-determination, with protective interventions traditionally revolving around degree of decision-making capacity of and risk of harm to the vulnerable adult. While common themes appear in situations of self-neglect, other circumstances and elements are unique to the individual, making the development of uniform protocols challenging, if not impossible and unjust.

Similarly, themes common to addressing self-neglect comprehensively emerged during the group discussions. The National APS Association has adopted a definition of self-neglect, but not all state laws contain the components of the definition. More problematic is that the term, or even the phenomenon, is not consistently recognized by other professional groups often involved during interventions, such as medicine and community policing. Neither are the general public nor policy-makers routinely aware of the risks facing these vulnerable adults. The policy group suggested that the term itself does not convey the severity of the condition and that another term be found. The social costs of self-neglect have not been identified and quantified. Research, especially about effective approaches, has barely

begun. The need for cross-training and across-the-board education about self-neglect and related issues, such as assessing capacity, arose frequently. The field of elder/adult protection does not have standardized tools and procedures for risk assessments and interventions. All groups recognized the importance and efficacy of interdisciplinary collaborations in dealing with self-neglect as well as the challenges in doing so. None of these challenges can be met without funding and national acceptance of self-neglect as a service area in elder/adult abuse programs, so passage of the Elder Justice Act was seen as an important step.

Ultimately, however, although interdisciplinary collaborations were deemed essential to achieving optimum outcomes for individuals, social factors --- societal neglect, if you will -- were acknowledged to present formidable barriers to preventing and resolving self-neglect. Elements of social justice such as access to health care, supportive housing, palliative care at the end of life, and effective mental health services are needed to form the foundation of a national approach to self-neglect.

Symposium on Self-Neglect: Building a Coordinated Response

Perspectives and Recommendations from Key Stakeholders

The Problem of Self-Neglect

Mr. Harvey's Circumstances: Mr. Harvey is seventy-four years old and lives alone in a suburban apartment building. He cannot remember his birthday or street address. He cannot tell the day of the week or current time. Mr. Harvey says that he plays golf daily, and indeed he owns all of the necessary equipment. However, neighbors report that he has not played the game in several years. They also express concern that Mr. Harvey keeps a loaded gun beside a large stack of money in the hall. Once he mistakenly gave his niece, visiting from out-of-state, a plastic bag of urine, after she asked him to unload the gun and give her the bullets. Mr. Harvey's speech is repetitive and his hygiene is poor. He seems unaware that the telephone has been disconnected and that the rent is past due. A look into his refrigerator uncovers very little food, and a look around the apartment reveals mounds of clutter, dirty dishes, and waste from two thin resident cats.

Nature and Scope of the Problem: Situations like Mr. Harvey's represent self-neglect, described by the National Center on Elder Abuse as when older people fail to meet their own physical, psychological, or social needs. Known by such other names as Diogenes Syndrome and social breakdown in the elderly, self-neglect has been discussed in scientific journals since the 1950s. It represents the most common problem reported to adult protective services (APS) nationwide. In the 2004 APS Survey of States, self-neglect among persons age 60 and over constituted nearly 30% of reports investigated and almost 40% of those substantiated. Nonetheless, it is controversial. The

National Research Council's Panel to Review Risk and Prevalence of Elder Abuse and Neglect did not consider self-neglect a form of elder mistreatment, largely because there is no perpetrator external to the older person him/herself. In addition, some self-neglecters choose a life style of health or safety risk and, unlike Mr. Harvey, have the capacity to make that decision, fully recognizing its potential consequences.

The National APS Association adopted the following definition:

Self-neglect is the result of an adult's inability, due to physical and/or mental impairments or diminished capacity, to perform essential self-care tasks including: providing essential food, clothing, shelter, and medical care; obtaining goods and services necessary to maintain physical health, mental health, emotional well-being and general safety; and/or managing financial affairs.

Cognitive impairment and lack of available or willing family care are risk factors evident in Mr. Harvey's situation. Other risk factors may include physical impairment, mental illness, substance abuse, social isolation, and poverty. The effects of self-neglect can be severe, such as injury, especially from falls, burns, and animals, or disease like pneumonia, gangrene, and malnutrition. Self-neglect even can result in death.

Symposium on Self-Neglect

Importance: Self-neglect is a critical issue for an aging society such as the United States, where older people increasingly reside alone and families are scattered about the country. It is a special consideration for older women, who live longer than their male counterparts and are more likely to have multiple chronic conditions and to be poor. There is need for better understanding of self-neglect and more effective responses to the problem.

These are imperatives for APS and the field of elder abuse and neglect. However, until now, no national forum has focused on self-neglect.

Purpose: The aim of the Symposium was to provide an interdisciplinary dialogue on self-neglect in order to identify salient issues and develop meaningful recommendations to guide related research, education, policy, and practice.

Sponsors: The National Committee for the Prevention of Elder Abuse (NCPEA) convened the Symposium as part of the National Collaboration on Elder Abuse: Connecting the Links, Filling the Gaps held June 22-25, 2006 in Houston, Texas. The first two days of the Collaboration were devoted to Training for APS Practitioners, held at the Hilton-University of Houston. The second two days consisted of the Symposium, held at the Crowne Plaza Houston-Downtown. Funding for the Symposium came from NCPEA and a donation from the Bailey Family Foundation. NCPEA's Education Committee, chaired by Bettye Mitchell, planned the event.

Participants: Attendance at the Symposium was by invitation only. The twenty-five participants came from eleven states and the District of Columbia. They represented the disciplines of social work, medicine, psychology, law, and criminal justice. Everyone had professional experience in self-neglect.

Process: NCPEA President Randy Thomas opened the Symposium. The first day featured a panel presentation by nationally recognized experts in self-neglect research and practice, facilitated by Wendy Lustbader, MSW. Carmel Dyer, MD, gave preliminary findings from her exploratory research on self-neglect. Rene Bergeron, PhD, discussed ethical dilemmas related to client safety and autonomy. Patricia Bomba, MD, focused on medical dimensions of self-neglect, particularly planning for end-of-life care. In the evening ,

participants viewed and discussed, facilitated by Georgia Anetzberger, PhD, three videos on self-neglect, including “Mr. Nobody” and “Packrat.” The second day was led by Bettye Mitchell, who challenged participants to address three questions:

- 1) What is our current understanding of self-neglect and where are the gaps in our knowledge?*
- 2) What recommendations can we make for improving understanding of and response to self-neglect?*
- 3) Can we suggest strategies for improving interdisciplinary and intersystem approaches to intervening in self-neglect situations?*

Participants were divided into discussion groups focused on research (facilitated by Georgia Anetzberger, PhD), education (facilitated by Holly Ramsey-Klawnsnik, PhD), policy (facilitated by Kathleen Quinn), and practice (facilitated by Mary Counihan, MSW). After the groups reported out and next steps were identified, the Symposium was adjourned.

Products: The Symposium had several outcomes. The event was acknowledged through press release and website listing. Proceedings and recommendations were developed into this final report, which is being disseminated by NCPEA. However, beyond tangible results, the Symposium:

- ❖ Provided the first-ever forum devoted to self-neglect*
- ❖ Assessed our current knowledge of self-neglect, identifying important gaps*
- ❖ Promoted networking and information sharing among experts in this field*

- ❖ *Stimulated interest in new research and better interventions directed at self-neglect*
- ❖ *Produced a national action agenda for improving our understanding and response to this complex problem*

Speakers

(Editors' note: the remainder of this paper was derived from notes taken during the symposium. Because the notes were not verbatim transcripts, the summaries that follow cannot be construed to capture the full text of the speakers' comments. The editors apologize for any inadvertent omissions or errors of fact.)

Carmel Dyer, MD

Carmel Bitondo Dyer, MD, is principal investigator of a National Institutes of Health grant on elder self-neglect. She served on the faculty of the Baylor College of Medicine for 15 years and is now Director of the Division of Geriatric Medicine for the Department of Internal Medicine at The University of Texas Medical School at Houston. In 1997, in cooperation with the Texas APS program, she set up a ground-breaking multi-disciplinary group, the Texas Elder Abuse and Mistreatment (TEAM) Institute. In 2003 she was named Physician of the Year by the Harris County Hospital District.

Dr. Dyer said that when she and her colleagues first began to work in the area of self-neglect, everybody told them that self-neglect was not an area of research in which to enter. In 1993 she had established a program that provided an outpatient clinic, inpatient treatment, and house calls. APS started using this new community resource, and Dr. Dyer, et. al., quickly found that instead of counting pills and taking blood pressure readings, they were visiting houses “carpeted with feces.” In one such removal, the client told the attending psychiatrist that she was OK; she lived in the Woodlands (an affluent suburb of Houston), and he declared she had capacity. The woman returned home; APS monitored the situation, paid for a complete clean up

and eventually removed the client again, this time to go live with a daughter in Oklahoma.

In 1997, Dr. Dyer formalized her relationship with APS with the establishment of the Texas Elder Abuse and Mistreatment Institute (TEAM), a collaboration among the Baylor College of Medicine, the Harris County Hospital District, and the Texas Department of Protective and Regulatory Services, the agency in which the APS program was situated. The TEAM grew, added disciplines, and by 2000 had clinical, research, and educational components. Dr. Dyer's initial interest had been stimulated when she heard Sue Bozinovski present the findings of her research on self-neglect at a meeting of state APS administrators held in conjunction with the Texas APS Conference. Dr. Dyer's study subsequently revealed that depression and dementia were independent risk factors for self-neglect. Her interest deepened -- why do people live in garbage and die, or almost die, for lack of help? She researched these questions via interviews with patients. During the study, the researchers noticed that the subjects (APS clients) enjoyed having company; they didn't want the researchers to leave, so the presence and interest of the researchers gave something back to the clients.

Over time, the TEAM gained access to the state APS data base and piloted new strategies to assist APS clients, such as telemedicine, using Houston as the laboratory. Access to the data base allowed the capture of pilot data, an essential for any research study, and contributed to the opportunity for a roadmap initiative, the Consortium for Research of Elder Self-Neglect in Texas (CREST), a select meeting of national experts convened by Dr. Dyer. The CREST conference immediately preceded the NCPEA self-neglect symposium and was held a year earlier than originally planned. The CREST participant group was deliberately held small in order to focus on

research. The findings of the study will be published in the proceedings of that conference.

In answer to the question, "Why study self-neglect?" Dr. Dyer responded that self-neglect:

- ❖ Comprises the highest percentage of allegations in the APS caseload,
- ❖ Has been found to be an independent risk factor for death,
- ❖ Appears to be associated with diseases of old age, dementia, depression, psychosis, and executive dysfunction,
- ❖ Is complex and requires inter-disciplinary collaboration,
- ❖ Does not have a common definition among the states, and
- ❖ Much remains unknown about factors that cause or contribute to it.

As such, self-neglect fit well into the priorities of the Exploratory Center for Interdisciplinary Research. Disciplines participating in the study were nursing, social work, geriatric medicine, gero-psychiatry, and Adult Protective Services from the following Institutions:

- ❖ Baylor School of Medicine,
- ❖ Houston County Hospital District,
- ❖ Texas Department of Protective and Regulatory Services,
- ❖ University of Texas school of Nursing,
- ❖ Texas Southern University,
- ❖ University of Texas School of Public Health,
- ❖ University of Texas Medical Branch,

- ❖ University of Houston,
- ❖ Harris County Medical Examiner's office, and
- ❖ National Aeronautics and Space Administration (NASA).

NASA was involved because of physical and emotional similarities between the study subjects and astronauts, e.g., loss of bone density, social isolation, and limited food choices.

The study development process involved establishing a case definition, describing the phenotype, and developing models. The plan included forming workgroups, setting a research agenda, and forming an external advisory board “to keep the researchers grounded.” The pilot projects included validating the self-neglect severity scale, completing geriatric and nutritional assessments, assessing muscle function, and testing for the presence of the gene allele APO E4.

Subjects in the study included people who were divorced, who were binge drinkers, and who avoided social gatherings and had no religious affiliation. They found no statistical differences in the cost of treating self-neglecting patients and those in the control group. The self-neglectors didn't overburden or tax the system; they didn't break the bank. They found discrete vitamin deficiencies (Vitamin D) and homocysteine excess, but not malnutrition. In the Kohlman Evaluation of Living Skills (KELS) test (*Can you write a check, read a bill?*), the self-neglectors scored worse than the controls. Thirty-seven percent of the self-neglectors were not experiencing depression or dementia.

The Self-Neglect Severity Scale revealed that neglect of one's physical appearance and environmental neglect didn't always occur concurrently;

only 23% of the subjects had a combination. Vital safety issues seemed to be key. The questions about self-neglect to be addressed in the study were:

- ❖ Social vs. medical factors,
- ❖ The feasibility of intervention (nutritionally),
- ❖ Validation of the self-neglect scale,
- ❖ Identification of brain abnormalities,
- ❖ Charting the clinical course,
- ❖ Assessing the role of executive dysfunction, and
- ❖ Determining how decision-making capacity can be screened.

Summary of Q and A

They screened for psychosis, chemical dependency, and depression and found prior chemical dependency (primarily alcohol).

They found that self-neglectors were more likely to say that they had pain.

They found an average body mass index of 28 in both groups. However, the numbers were skewed by several morbidly obese patients.

They looked at health care costs and need to discuss this in the paper.

Both groups were financially impoverished, but Dr. Dyer was not able to report whether the study subjects were able to keep up with their finances. However, this information can be teased out of the data, and persons wanting it should contact her.

Rene Bergeron, PhD

Rene Bergeron, PhD, is an associate professor at the University of New Hampshire with 25 years of practice that include 11 years in hospital social work, when she began interfacing with APS. She continued working with APS as chair of the New Hampshire Elder Abuse committee, which she left in 2005 in order to focus on teaching and research.

Dr. Bergeron has written an article, "Self –Determination and Elder Abuse: Do we know enough?" that appears in the Journal of Gerontological Social Work, Volume 46. Dr. Bergeron questions whether the social work field fully understands self-determination when clients are in situations of severe abuse and neglect. APS says, "The client has the right to make bad decisions," but the questions left unanswered have to do with the level of risk to the client, the ability of the client to make appropriate decisions given the circumstances, and the ability of the client to execute his/her decision(s). Bergeron reviewed newspaper articles from the summer of 2004, finding that most talked about the incompetencies of APS workers with regard to self-determining clients. Thus, there is a misunderstanding of the public's view of how APS uses self-determination and the implication that the public views level of risk to be a predominate concern. Such articles are detrimental to the ability of APS to carry out its purpose, because they:

- ❖ Suggest the liability of APS agencies,
- ❖ Create distrust of the system meant to provide assistance,
- ❖ Expose the private lives of very vulnerable people,
- ❖ Increase distrust of policy makers in Adult Protective Services, and
- ❖ Move decision making into the courts, further impinging upon client self-determination.

Bergeron fears the attitudes expressed in such press coverage could cause APS to lose its role to judges and lawyers who may want clean "black and

white" solutions, which will erode clients' ability to choose within a realm of possible alternatives to reduce severe risk.

Dr. Bergeron spoke of a case in Arkansas that has received national exposure. Both the son and APS were on trial. The son received a 20 year sentence, and the public defender accused APS of failing the client because it had an active case. Now more lawyers are getting involved in wrongful death suits, and APS is a potential target. "APS was more interested in mental capacity than the woman's physical safety," critics alleged. This controversy resulted in the Arkansas state legislature's assessing the program.

The ethical debate then becomes "What should determine professional intervention?"

- ❖ The National Association of Social Worker's Code of Ethics (1999)?
- ❖ Professional judgment (or fears)?
- ❖ The client's verbalization of what s/he wants?

At what point is intervention necessary? When does it become an unnecessary imposition of values not in accordance with those of the client? Bergeron surmises that professionally we fear that we will:

- ❖ Impose our professional values onto the lives of clients,
- ❖ Diminish the client's ability to choose for him or herself,
- ❖ Put the "interpreted" good of the community over the good of the client (overregulation), and
- ❖ Make decisions for which we will be held professionally accountable to the client and the community -- what if we are wrong?

Dr. Bergeron stated that self-neglect is an American, white, middle-class notion based on individualism. She pointed out that couples that operate this

way typically divorce. She argued that community good is a necessary piece in all decision making, and that self-determination promotes individual gain/desire over the notion of the common good, because it:

- ❖ Places less emphasis on the interrelationship of individual rights with that of the community good,
- ❖ Promotes individual gain/desire over the notion of the common good,
- ❖ Encourages self-realization without consideration of group-oriented values,
- ❖ Eliminates practicing from an ecological perspective, which is the backbone of social work practice, and
- ❖ Implies that choice comes from an individual base of power vs. an isolation or a sense of aloneness and helplessness (as seen in disenfranchised groups).

Allowing self-determination implies that there is an offering of appropriate choices and requires the acceptance of two concepts of liberty: making choices without interference and the ability of the individual to make rational choices. Regardless, Bergeron stated that in the end, the individual practitioner will be held accountable for what is done or not done. Therefore it is imperative for the social worker to document his or her decision-making process.

Canada has held competency clinics for years in some locations. These clinics provide more thorough assessments of individuals who are self-neglecting. The clinics take a comprehensive approach that involves the legal community, health care workers, ethicists, clients, families, and others as needed to reach consensus. Interdisciplinary teams are most effective in elder abuse case reviews, death reviews, task forces and for consultation. Additionally, Bergeron held that self-determination is but one principle of

practice, along with workers not abandoning clients and doing the least harm. Depending on the level of risk to the client, workers may need to negotiate a solution that minimizes the risk to a more acceptable level of safety. Bergeron concluded that "self-determination does not necessarily mean total client autonomy, but may be viewed within a framework that ensures client involvement based on levels of safety, risks, capacity, and family and community good."

Discussion

Anetzberger: Allow me to play the devil's advocate. A lot of what you are proposing is contrary to the legal system *vis a vis* individual rights, the "It's all up to you" credo of individual values in our culture (e.g., Horatio Alger). In the early days of conceptualizing interventions in elder abuse, APS took the path of beneficence over autonomy and was criticized widely (e.g., John Regan). Then early research suggested flawed outcomes. Given what I just said, how do you suggest getting there?

Bergeron: The fear of yanking people out of their homes was impeding appropriate interventions. In New Hampshire, APS workers have zero money for training; special grants are needed in order for them to get training. APS workers MUST have solid training, so they are not afraid to begin making assessments. They fear that they do not know enough, when in fact they know more than anybody. We need to instill knowledge, consulting practices, teams, and case rounds. We have to get over the notion of protecting the client's privacy when it prevents consultation. We're just trying to raise the safety level, not necessarily totally reverse the situation. We have to share the burden.

Counihan: There is a bit of fear in the San Francisco APS program, which is staffed exclusively with Masters of Social Work and Registered Nurses,

around unintended consequences and having the client pay the price emotionally. We in the program are extremely troubled by the reactions of the press. When the public hears about something in the abstract, e.g. a case in San Francisco of a woman who had lived in a neighborhood all her life, was totally isolated from her family, and allowed drinking buddies to stay with her. She was clean, bathed, got to medical appointments, and had no health problems. But young kids doing drugs in the same location posed some risk, and the community was outraged. The idea that APS is going to make decisions based on what the public thinks is scary! APS shouldn't make policy decisions based on media attention.

Patricia Bomba, MD

Patricia Bomba, MD, is a Geriatrician and the Vice President and Medical Director of the Lifetime Healthcare Companies. The company is a non-profit health plan whose mission is making a difference in the community in which it serves. Dr. Bomba has been in practice 18 years, including six months in a nursing facility. She now works on improving end-of-life (EOL) care and pain management.

On the last leg of her plane trip to Houston, Dr. Bomba spoke with a young Houstonian who shared a story about his grandparents. His grandfather had Alzheimer's Disease and was cared for at home until his death. The young man talked about the stages of the disease; he could frame the phases. They struggled with taking the car keys away; the grandfather wandered by car to Oklahoma. Now that her husband has gone, his grandmother is depressed, has lost interest in life, and is waiting to die.

Bomba reminded the group that patient and family units may not necessarily be biologic. She recounted her experience of being the MD of record for Medicare/Medicaid patients with no other insurance, when a

patient had decubiti down to the bone. The son had left his mother lying on newspaper, which he changed once a day.

Bomba urged a more careful look at economic data, because she suspects that Dr. Dyer's analysis may not be quite correct. For example, in the situation she just described, the woman was in the hospital for six months with severe infections and eventually died. Because the son didn't really know any better; he was not educated, and there were no resources, she classifies this case as neglect by us as the community.

Bomba showed photos of a gangrenous hand and of houses filled with trash, explaining that medical doctors do not see without the eyes of the community. Some clients were basically stubborn; they were intact cognitively and didn't want to pay to have their homes cleaned and cleared of vermin and animals.

Bomba remarked on the association of self-neglect with cognitive disorders and suggested that self-neglect be maintained in the differential diagnosis as a way to ensure that doctors look for it. Her clinical observations include patients who:

- ❖ Wear the same dress to the doctor every time, i.e., the "doctor's dress,"
- ❖ Have "pretty obvious" body odor, and
- ❖ Refuse to be examined.

However, Bomba noted that even geriatricians can miss self-neglect. For example, early in her practice in the late 70's or early 80's, they didn't talk about activities of daily living (ADLs) and incontinence. Bomba got a call from APS about a woman being evicted because her home was being condemned. The woman had run a microbiology department, had worked

for Talbot's, and volunteered in the community. The slides Bomba showed earlier were from this woman's house.

Bomba identified the challenges of discriminating between hoarding versus clutter versus personality characteristics, such as in stubborn clients who have burned out and turned off their families. She asked how APS can get clinicians to understand and refer, to realize that changes in patterns may signify executive dysfunction and cognitive impairment. She mentioned the barriers presented by the Health Insurance Portability and Accountability Act (HIPAA) in clinical practice, remarking that privacy existed before HIPAA.

Bomba stated that geriatric capacity assessments are not well done and that geriatric syndromes are not recognized. We need education focused on explaining capacity, how it is determined, and what can be done with capacity assessment. We also need whole-person assessments that are interdisciplinary and interdependent.

Bomba considers the lack of palliative care to be a form of elder abuse and recognized the association of self-neglect with the lack of pain management and advance care planning and the cost of care at the end of life. She said that pain is the leading reason people seek care; it is the cause of eighty percent of all doctor visits and the leading cause of disability. She believes that pain is under-treated in general, and even more so with incapacity, especially for patients with a history of alcoholism.

Bomba discussed the costs of under-treated pain and its impact on the quality of life. It leads to medical complications and prolonged recovery time. As chronic pain progresses, cognitive function can be compromised, socialization and the quality of life decrease, and functional ability is impaired.

Permanency planning means whole-person planning: powers of attorney, advanced directives, Physician Orders for Life Sustaining Treatment (POLST), guardianship, Medicaid and financial planning, and other practical issues. The lack of capacity adversely affects the whole process.

Wendy Lustbader's Response to the Panelists

Wendy Lustbader, MSW, lectures nationally on topics related to chronic illness, aging, and the needs of family caregivers. An Affiliate Associate Professor at the University of Washington School of Social Work, she is the author of Counting on Kindness and What's Worth Knowing and the co-author of Taking Care of Aging Family Members: A Practical Guide.

Lustbader began by asking if there was anybody in the room who was not self-neglecting. She remarked that self-neglect is part of our life cycle, and the penchant for self-destruction is part of the human condition. She suggested that the reasons why we neglect ourselves may fall into a continuum:

Ignorance/denial – as with the person with diabetes who would not stop eating sweets, saying “It’s my body and my life. I want you girls to back off!” Lustbader also pointed out, given the difficulty of understanding medical situations, that the difference between ignorance and denial can be murky.

Anxiety – which we quell with food, alcohol, cigarettes, and other addictions.

Comforting grief – grief overload can throw someone into serious self-neglect, as in, “Because my grandmother just died, I’m going to eat this whole bag of salty potato chips.”

Immediate gratification – as in *I’ll Quit Tomorrow*, which Lustbader considers the best book on alcoholism.

Biological depression – this runs in families, and we do not know its true extent. It's marked by a quiet sense of disengagement with others, hopelessness and despair, as in, "I do not care, I might as well... [practice the root of self-destruction]."

Exercising the right to commit slow suicide — Fast suicide is prohibited, and intervention is involuntary. Lustbader referred to Bergeron's list of circumstances in which we deprive people of autonomy, such as in failure to thrive and grave disability, mentioning clauses in Washington and California laws. She recounted the story of trying to help a woman who was on the road to slow suicide. This person was diabetic, grief-stricken and eating cookies. However, the response of mental health was, "Call back when it's immediately life-threatening."

Lustbader deplored the inadequacy of the mental health system and how it totally neglects people who are homebound. Oregon at one time sent mental health teams on home visits to elders, including self-neglectors, but the program is terminating due to lack of funding. She stated that APS workers all over are crying for help from the mental health system, and that her presentation the previous day to Texas staff who are subject matter experts on self-neglect was an attempt to make up for the lack of adequate mental health systems.

Chemical dependency — This system has a lot of implications for our subjects and is in disarray across the country. Lustbader described a publicly funded alcohol/drug center that would treat first offenders. She could motivate a victim by promising that her son would have good, court-ordered treatment. However, the program was deemed too expensive and was shut down.

Lustbader is frustrated about the debate over self-neglect as a subcategory of elder abuse, because she feels that choosing to continue to live in an abusive situation is self-neglect. We have decided that the structure of CPS and APS will be different. We can remove children, but we allow self-determination by the elder victim.

Lustbader suggested that participants look at self-neglect in terms of these the following categories, which may co-exist:

Caregivers — who neglect their own needs while taking care of others. Lustbader said that she would never forget entering a very tidy house pervaded by the odor of infection. She sniffed around and found that the smell was coming from the caregiver's leg. When asked about her leg, the wife said, "Oh, it's OK. I have a little bit of a sore there, but it's OK." The infection was so severe the caregiver had to be hospitalized. Lustbader mentioned a study of caregivers of people with dementia that found that caregivers took longer to heal than the control group.

Depression — which Lustbader intentionally categorized separately from mental illness, alluding to the kind of depression that relates directly to self-neglect — loss of purpose, of will to live, of meaning — quoting Nietzsche, "He who has a why to live can bear with almost any how."

Mental Illness — e.g., schizophrenic ideations.

Chemical dependency — the elders themselves may be dependent.

The discussion of mental illness and chemical dependency segued into a discussion of hoarding. Eighteen months prior, Lustbader had read all the research on hoarding. She disagreed with it because she found it so muddled

and developed her own model for understanding hoarding behaviors. She noted that individuals may display combinations of these patterns.

Accumulators — Persons with underlying, untreated mental illness, including dementia and loss of executive function. Lustbader described them as “Basically passive... they do not throw things away.” They have lost the ability to distinguish garbage from non-garbage, and the house fills to the brim with disgusting things. People with schizophrenia have all sorts of ideations about their accumulations. (She noted later that her study did not include people with paranoid schizophrenia.)

Hoarders — Persons who keep things because they might need them someday. They fill their houses with things that have an urgent use or are fulfilling a need. She finds that these individuals are survivors of the Great Depression. For such persons, hoarding means security.

Collectors — These persons will have a distinct thing that they collect, such as MacDonald's lids. Meaning is attached to the thing itself. It may be important for making art, for example.

Lustbader described the stages of the behaviors as mild, medium, and severe. In the mild stage, the clutter is contained. In the medium stage, the clutter is starting to intrude into other areas of the home. In the severe stage, the person becomes socially isolated and the hoarding is unconstrained, with “stuff” taking over the dwelling.

General Discussion after the Presentations

Some schizophrenics do not hoard and lead stable lives in remission, due to the efficacy of new medications.

Per Randy Frost, we see so many factors and individual variations in the onset of accumulating/hoarding/collecting behavior; we must be able to

discern and evaluate the cognitive and emotional dimensions of the relationship of the person to the things being collected.

A task force in New Hampshire has developed a website, "Awareness and Prevention of Elder Substance Misuse," <http://www.eldersubstancemisuse.org>., and visitors have permission to use its materials.

A participant whose son has fragile X syndrome with obsessive/compulsive behavior spoke of his leaning toward hoarding, but having social controls. She has learned to categorize items in the clutter according to the level of stress (ranked from 0 to 5) that he would feel if they were removed. Then, rather than asking him to decide what to throw away, which puts his stress level at 5, she uses the ranking to decide and removes the things when he is away. His stress level is at 3 when she does this, but it goes back down to 0 in a day.

She strongly feels that social workers MUST NOT ERR ON THE SIDE OF DOING NOTHING. They are the only arm of society reaching in. She wonders what will happen with her son when she is no longer his social agent?

"We're not going to be able to write protocol books for this. It has to be individual." In other words, it is the responsibility of the worker/guardian to learn the history of how this person has lived and his/her values, in order to assist the client in the development of an appropriate approach to intervention, which will vary from client-to-client, situation-to-situation.

The literature talks about "making the mess manageable." Everybody who hoards does not have obsessive-compulsive disorder. For example, seniors who lived through the depression learned to value everything, and they still do. They will keep scraps of saran wrap and aluminum foil. It's against their value system to throw it away, and doing so devalues their experience.

Hoarding is a final common pathway for a number of conditions. We need to perform careful lines of inquiry.

One would think you could develop specific lines of intervention; there seems to be a great deal of overlap, and also outliers. How would you handle these?

Perhaps tomorrow we can develop real action steps, ideas for what can be done, state, by state, for people in these categories. If not, then perhaps we can at least bear witness to the problem.

People also need to think about elders in the community drinking themselves to death, when these individuals are not wanted in treatment programs.

Practitioners also encounter caregivers with depression. How can APS workers become jacks of all trades for these clients?

It might help to think in terms of preventive approaches, such as partnering with Alzheimer's Associations to devise strategies for families who are struggling to keep parents at home, when the parents are really resistant to services. How can we do some prevention, so the cases do not ever get to APS?

With regard to the idea that living with abuse is a form a self-neglect — does not this sound like we are blaming the victim, as in “Why does she let this happen?” It can be misunderstood in this light and we need to keep this from happening. Also, there's the whole issue of undue influence — how does this play in to self-neglect?

At what point do we say that the right to folly is so self-destructive that it cannot be permitted? As in, “I would rather let Johnny beat me up every night than see him go into the prison system.” This speaks to a flaw in the legal

approach. What if we could provide some services to Johnny? The law sets up a perpetrator/victim dichotomy. When the social worker had something to offer Johnny, intervention with the mother was very effective.

The more we cut services, the more self-neglect we are going to see — self-neglect due to system failure. What are we going to do in the meantime until the pendulum begins to spring back? It hearkens back to the days of Franklin Delano Roosevelt — one-third of our nation is ill-housed and ill-fed, and we need a social program to address this.

Breakout Groups

Following the presentations by the four speakers, the participants were divided into four discussion groups — Research, Policy, Practice, and Education — and asked to answer the following questions regarding self-neglect:

- ❖ What is needed (assessment)?
- ❖ What is needed now (short-term goals)?
- ❖ What is needed most (priorities)?
- ❖ What is needed to make this happen (strategies)?

RESEARCH ISSUES AND RECOMMENDATIONS

We begin with the research group's report, which most closely adhered to the desired format.

What is needed?

- ❖ What are the research questions?
- ❖ What is the social and health care cost?
- ❖ What is self neglect?
- ❖ What is the impact of not doing a whole person approach?
- ❖ Can we apply family preservation to APS practice?
- ❖ Is APS the right party to deal with this population?
- ❖ What approaches are most effective?
- ❖ How is APS identifying self neglect?
- ❖ What are the markers?
- ❖ What is the spectrum?
- ❖ How do you intersect with other agencies in treating self neglect?
- ❖ Is it reasonable to talk in terms of us all being in the state of self neglect?

What is needed in the short term are answers to the following questions:

- ❖ What has been helpful in terms of interventions?
- ❖ What are the societal costs related to individuals who are self neglecting?
- ❖ What are the outcomes of intervention in dealing with the self - neglect population?
- ❖ How do we communicate what we know to the general public and how do we control its dissemination?
- ❖ How do we educate other professions as to why they should care about self neglect?

What's needed most are:

- ❖ Clarification of the definition and its application to other professions,
- ❖ Identification of social costs,
- ❖ Identification of implications for public policy, and
- ❖ Concrete knowledge about what works/does not work in addressing self-neglect.

What is needed to make it all happen:

- ❖ Engaging potential funding sources,
- ❖ Establishing more partnerships between APS and universities and researchers, and
- ❖ Involving companies through Employment Assistance Programs.

Recommendation:

- ❖ Identify experts and researchers and develop a forum to create strategies to address the issues.

POLICY, PRACTICE, EDUCATION ISSUES

Due to significant overlap among the three remaining groups, we have combined their issues into one list, as follows:

- ❖ Need for acceptance of a common definition of "self-neglect," differentiating these adults from the general population,
- ❖ Lack of education of professionals on the severity of self-neglect,
- ❖ Lack of a national system for developing, funding, and overseeing guardianship programs,
- ❖ Absence of a standardized approach and tools for assessing self-neglect,

- ❖ Lack of comprehensive interdisciplinary policies inclusive of other forms of abuse,
- ❖ Limited training opportunities to increase the awareness of first responders,
- ❖ The term “self-neglect” not sounding sufficiently serious,
- ❖ Lack of a standardized and nationally adopted risk assessment tool,
- ❖ Lack of adequate and inter-disciplinary staffing for high risk cases,
- ❖ Limited APS staff knowledge of other disciplines and related service providers,
- ❖ Lack of working relationships between APS and code enforcement,
- ❖ Lack of funding for evaluation and treatment,
- ❖ Failure to work with experts and integrate current research and knowledge into practice,
- ❖ Limited ability of APS to purchase services for perpetrators and family members,
- ❖ Language and cultural barriers among professionals,
- ❖ Lack of consistent and comprehensive training and education for academicians and practitioners,
- ❖ Lack of quality training for practitioners who encounter APS situations,
- ❖ Lack of awareness and knowledge about self-neglect among policy makers,
- ❖ Failure to evaluate program goals and implementation, and
- ❖ Lack of qualified ethics trainers.

POLICY RECOMMENDATIONS

- ❖ Re-evaluate the term “self-neglect” and consider identifying another term that conveys the actual definition and the severity of the phenomenon.
- ❖ Support the passage of the Elder Justice Act, which includes self-neglect as a service area.
- ❖ Establish guardianship programs nationwide.
- ❖ Develop and implement a standardized approach, tools, and resources for practitioners to use for screening risks and assessing capacity. This approach should be designed to assist the practitioner in determining whether the person understands potential risks and identifying next steps for the practitioner to take.
- ❖ Develop a comprehensive, standardized, risk-based screening, in addition to assessing capacity, recognizing that self-neglect feeds into other forms of abuse.
- ❖ Develop a national policy around self-neglect that includes the participation of the Department of Justice and law enforcement in order to ensure an interdisciplinary approach and recognize and support the role of community policing in dealing with situations of self-neglect.
- ❖ Eliminate age as an eligibility criterion for protective services, using risk-based criteria instead.
- ❖ Fund state programs so that APS can be accessible 24/7 nationwide.

PRACTICE RECOMMENDATIONS

- ❖ Develop a standardized risk assessment tool and adopt it nationally.
- ❖ Ensure internal staffing of and use of Inter-disciplinary teams (IDTs) in high-risk cases.
- ❖ Ensure staff is educated about other disciplines and service providers in order to enhance communication.

- ❖ Ensure APS and code enforcement work together.
- ❖ Identify the knowledge, skills, and abilities necessary to be effective in APS in order to facilitate hiring appropriately.
- ❖ Educate and increase awareness among funding authorities.
- ❖ Seek revision of Medicare and Medicaid regulations and funding to allow reimbursement for home visits of mental health workers.
- ❖ Expand ability of APS to purchase services for perpetrators and family members.
- ❖ Look at self-determination and how it affects practice. Self determination should not be an either/or, the field needs to move toward more complex models.
- ❖ Recognize that "APS is only as valuable as the resources and services that exist."

EDUCATION RECOMMENDATIONS

- ❖ Develop and conduct comprehensive training and educational opportunities for academicians and practitioners, including law enforcement.
- ❖ Improve advanced and specialized training for practitioners.
- ❖ Ensure training is developed to address knowledge, skills and abilities and the overall goals and objectives of APS.
- ❖ Develop and conduct training for policy makers to increase knowledge and awareness.
- ❖ Develop comprehensive plans to evaluate trainings.
- ❖ Evaluate the implementation of skills and abilities gained through trainings.
- ❖ Conduct outcome evaluation to assess level of change.
- ❖ Empower NAPSA to maintain a national training register.
- ❖ Develop national training standards.

- ❖ Work with universities to expand current curricula in social work, medicine, nursing, law schools considering legislative initiatives for effectiveness.
- ❖ Develop trainings to increase awareness and enhance skills of first responders.
- ❖ Increase education on “self-neglect” and its relation to other forms of abuse.

Summary of Large Group Discussion - Sunday June 25, 2006

Self-Determination

An intelligent, educated, reasonable person could take two possible impressions from Dr. Bergeron's talk --

Impression A: Rene is saying that there are times when people technically, legally might retain capacity to make informed decisions, but are in such dire situations that we have to intervene anyway.

Impression B: The person is in a dire situation; the APS worker sees this person, asks superficial questions (e.g., determines if the person knows the president and his/her own name and address), makes a premature and erroneous assumption that the person has competence and accepts the refusal.

Which was intended?

Probably a combination of both – these questions are raised for the practice community because we are dealing with vulnerable people and we have failed many of them, partly because of how we view self-determination. I think it's been under-explored; our culture is not to talk about it. Talking about it raises the questions that you are asking. None of us wants to be labeled paternalistic, but I do not think that victims necessarily retain the right to make decisions exclusive of their surroundings. When another person, a professor, sees immense suffering and the person is refusing all kinds of intervention, this raises a red flag. So much in the literature points to that.

Assessing Capacity

I am not sure that any professional group is quite qualified to measure capacity, because it is so impurely understood. I am advocating for an inter-

disciplinary approach to open the debate. These types of cases present huge dilemmas for APS, and being in huge discomfort about a case presents a red flag for practitioners. What is missing in practice?

The missing element is that asking about the name of the president does not deal with the task at hand. This kind of question fails to look at the decision at hand.

It's important to realize that APS workers cannot assess capacity, but they can assess whether someone needs an inter-disciplinary geriatric assessment. What we have not learned is how to get to the questions that really relate to whether the person understands the situation, has the ability to make a choice, and so on.

Absolutely, this is correct. APS does not have people in the field who can assess capacity. Even with the array of degrees among workers, many are comfortable using the mini-mental status exam (MMSE). Although the MMSE is not appropriate for this purpose, many courts require it to be administered and are appalled if this hasn't happened. This is an extension of the issue of assessing capacity.

Getting a capacity assessment when the subject does not want it violates self-determination. However, not only the individual's pain and suffering may override self-determination, the common good may do this as well.

Let's start talking about APS screening, not APS assessing capacity. Screening means different things in different settings; I agree that APS should be screening rather than assessing capacity. The gold standard for assessment is with psychiatrists. The MMSE has nothing to do with capacity. We must not look at a person's capacity to do only one thing. Capacity needs to be assessed for each task that pertains. Even if the person is

completely demented and does not recognize his/her own son, s/he still may have the capacity to do other things. Maybe psychiatrists should administer a standard psychiatric assessment for every person they see!

Assessment is an important piece. There are times when you do not have an assessment, the person lacks capacity, and you cannot meet their needs because they will not cooperate. But this is not the only piece of it. Some of it is money; we do not have the services that clients need. Other times the pressure is to figure out ways to get people to accept the services that we can offer. Figuring out better ways to be more successful is a huge challenge for APS.

On the other hand, we shouldn't be too focused on capacity, which comes into play mostly when someone is refusing and you are trying to decide whether and how to intervene. What's core is assessing risk and deciding how you can reduce the risk. Let's not forget about the other 97% of situations in which we are not trying to do something involuntary. If the risk is not high, you may not do anything at all. But with dire risk, capacity becomes more important. For the most part, APS work is voluntary.

While I agree that APS workers cannot assess capacity, in working with APS staff, I find that we as a society put the APS worker between a rock and a hard place. We tell them they cannot do it, and then we ask them about the person's capacity. The challenge for us as a group is to help take APS out of this spot. We need tools, methods, guidelines. When we find a person with dire needs who seems to be competent, all the first responders need something better than the mini-mental status exam. We need better screening tools and training. We do not give APS worker the tools, the training, and the supervision to do the job properly.

Training

Quite often a psychiatrist may not know how to do a capacity assessment, because they look only at cognitive, not functional, ability. Also, we have to look at the prevention of self-neglect. Why aren't we training professionals (including first responders, mail deliverers, etc.) to intervene earlier? Why are we not training them more?

Houston has a Gatekeeper program that trains such people to recognize and report possible situations of elder abuse and neglect. APS helps with the training. Perhaps gatekeeper training could be a part of the training recommended nationally.

There are all different kinds of gatekeeper programs. Why cannot we get together?

Across the country we are going to have to change the way that people are trained. We have to get on the side of some kind of resource development. When universities are willing to help, we need to tap into those resources. What we've been doing here in Houston has made a lot of difference, and it didn't take whole lot of funds. The majority of the help we receive is *pro-bono*, through partnerships.

One of the main challenges to reaching self neglectors is time. You need to visit frequently and get them to trust you. Ending the social isolation is a big factor in successful resolution. APS should get pre-med college students to volunteer, in return for a recommendation. We have found that our clients absolutely love getting visits from interns, physicians, and medical students.

To build on what is being said, CPS latches onto Title II money for to fund placements in CPS agencies, in return for the student's working x amount of years in CPS. We need to create a similar program for APS to get people into the field. (TX APS now has a stipend program.) Clients are proud to be helping young people get their education; it bolsters their self-esteem. The APS

community needs to make a decision about kind of degree that best serves the field – is it family studies, social work, nursing, or some combination? We need some form of uniformity from which to begin. The APS training for a social worker is different from that needed for a history major.

Appropriations in Texas for additional APS staff have resulted in each region's hiring of specialized staff assigned to community development: a Community Initiatives Specialist and a Resource and External Relations Specialist. This has resulted in a significant increase in the involvement of community and professional groups with APS. Not only is this cooperation *pro bono*, it fills training and resource gaps pertinent to working in teams.

Definitions

A gap is caused when the assumption is made that there is clarity around the definition of self-neglect. This was clearly the case when Wendy went over her practice categories. However, the original concerns in the field of elder abuse were about clarity of definitions and terminology. So often we see self-neglect used in the same manner as self-abuse; they can be used interchangeably, even though Diogenes' Syndrome is different.

Beyond community, the patient/family unit is critical. Wendy's analysis broadening the definition of self-neglect does help provide linkage to other organizations in terms of prevention. The spectrum of self-neglect starts at wellness and goes to severity and death. Other missing elements are dealing with people with Alzheimer's disease and memory disorders. Earlier someone alluded to APS' not being able to deal with social justice and system failure. However, unless we wrap our arms around that concept and call the question of social justice, we'll always be in this situation. Our system is wasting money on futile care. Spending more dollars does not necessarily mean better quality of care or greater patient satisfaction. We have to talk about social justice

Relationship to Other Forms of Abuse.

Experience indicates that being in a state of neglect puts the person at high risk for other forms of abuse. What percent of self-neglecting elders get victimized in other ways? Could self-neglecting behavior be an individual's attempt to protect themselves? Might they refuse would-be helpers for fear of what the helpers may do?

Someone at the CREST conference reported that they have found to date that $\frac{1}{4}$ of self-neglecting elders have some history of victimization. We are not sure that we know the whole breadth of that. We do not know if self-neglect is the risk factor, or if the aftermath of victimization leads to self-neglect, out of despair and hopelessness. We do not know where one starts and the other ends – are there things that would affect the behaviors (e.g. nutrition) that can be done to make the victimization less likely? How do we respond – not just APS, but criminal justice? Criminal justice does not see self-neglect as its business, but we may need to reconsider and look at the cases differently.

Actually, some of the preliminary findings show less combination of self-neglect with other forms of abuse. It would be interesting to have the findings of a longitudinal study.

Some are concerned that CREST had limitations in its scope and types of clients. We are not sure that we have the whole picture. Within the accumulator/hoarder/collector categories we find scams adding to the clutter. In California they found six companies under one umbrella that were scamming with magazine sales. Also irksome are the requests for donations from religious organizations. The state Attorneys General have various amounts of clout. Necessary to getting allocations is finding out what money is available globally. We do have good data, for example, about regional

variations in cost of care at the end of life. It's clear that spending more money at the end of life does not equate to quality of care or greater satisfaction.

Another question is whether self-neglectors are easy prey for types of crimes that do not usually fall into APS purview. Anyone can be at risk from frauds and scams *versus* someone's being self-neglecting because they are already a victim of their caregiver.

Self-neglectors may be perpetrators as well, such as when a caregiver's ignoring an injury or impairment leads to elder abuse.

Cost of Intervention/Not Intervening

What ever we come up with, it shouldn't address only this generation of elders. We should consider what the baby boomers will need; they are at greater risk because of their history of risky behavior and differences in the family in this era. We have to consider the cost. How much is society willing to pay on behalf of persons who elected to have the risk in their life-styles?

The *New Yorker* recently featured a story about the homeless initiative in New York City. Research on people using homeless shelters found that 90% of the people coming through the shelters were truly temporary -- 2 nights stay on average. The researchers then followed the 10% who were not temporary in order to see what they were costing the medical system. In response, they developed an incredibly intensive program that provided the chronically homeless people rooms in the basement of a building. They employed social workers, nurses and in-home helpers to provide intensive, daily contact and supervision to keep these individuals off the street. What the article found was that such services significantly decrease medical expenses, but it challenges the morale stance of helping the deserving.

Therefore, justifying the social services expense with taxpayers will present a challenge.

Regarding ways to get the self-neglecting client to accept services, the film, *Mr. Nobody*, represents the challenges, because it depicts all sorts of system failures in the intervention on his behalf. So often, the literature around self-neglect focuses on non-compliance. Actually, when you look at what has been documented so far about the outcomes of intervention, you find that from 33% to 70% of self-neglecting clients end up in nursing homes. Agencies have to deal with workload issues with staff. You cannot have the expectation that someone is to do this job (across the disciplines) properly if the workload is so large that they cannot do the things they need to do. Frontline staff shouldn't be the ones having to prioritize.

Regarding the cost issue, it seems that because self-neglectors avoid the medical system, they surface in egregious situations that are costly to treat. Maybe the long-term study will reveal more costs. If we can prove what the care costs, then we've got a leg to stand on when appealing for prevention and early intervention.

This would be similar to the early days of legal services development, when they demonstrated that having legal services saved money. The Elder Justice Act would try to determine what early interventions by APS could save the federal government. This can be done without a huge study; any provider could do this; we've got to make the effort.

Remember that many medical reasons for self-neglect are reversible. Many folks regain capacity after treatment.

We cannot forget that often we have to compromise; we may not be able to do 100% of what is appropriate for the patient. Compromise may be the way to go.

In research terms, the sample in Dr. Dyer's study is a sample of convenience, rather than a random sample from which a scientific generalization can be made. Demographics are going to be hugely important. If she can prove that with certain populations, no increased costs are associated with intervention, we would have a powerful argument that such interventions are worth funding.

With these remarks, the meeting ended. The National Committee for the Prevention of Elder Abuse is grateful for the contributions of the following participants, without whom the symposium would not have been possible.

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