

Responding to Self-Neglect in Vermont

DEPARTMENT OF DISABILITIES, AGING, AND INDEPENDENT LIVING (DAIL)

Prepared by Kelly Melekis, PhD

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Introduction and Background

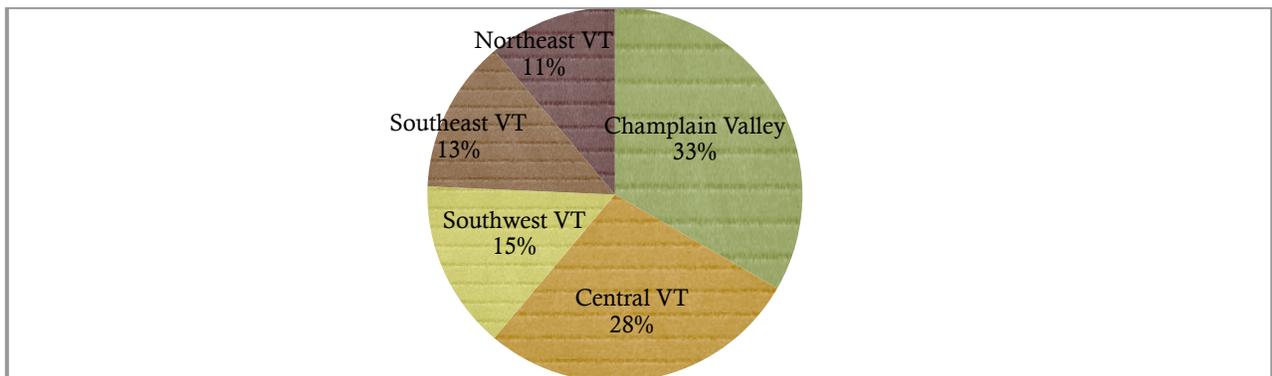
A study of self-neglect was conducted to enhance understanding of the issue of “self-neglect” in Vermont. Goals of the study were to 1) estimate the number of individuals less than 60 and 60 or older who can be described as self-neglecting and 2) gather information to inform a plan to enhance coordinated community response to self-neglect.

Methods

The study utilized a non-experimental survey of service providers and key stakeholder interviews throughout the state. Providers were recruited via purposive and snowball sampling, with DAIL and each Area Agency on Aging (AAA) recommending local providers to receive the survey via email. The email survey invitation included a weblink to the survey for providers to share with colleagues. A survey weblink was also included on several provider websites and social media tools, such as facebook pages, and distributed via provider and partner lists at several agencies. Providers represent entities conducting programs that receive assistance under the Older Americans Act (OAA), those conducting other Federal programs for older individuals, as well as programs that serve a much broader community population, of which older adults and caregivers are included.

Both the survey instruments and key stakeholder interview protocol were designed by the researcher, in conjunction with DAIL Division of Disabilities and Aging Services (DDAS) staff and AAA Directors. The service provider survey was distributed for one month (mid-September to mid-October, 2013), with reminder emails sent weekly to encourage completion. There were 137 respondents representing all areas of the state and a proportional distribution (Figure 1). A total of 36 stakeholders throughout the state were interviewed, out of 68 who were invited to participate. Survey data was analyzed using SPSS. Interviews were transcribed and then analyzed using content and thematic analysis methods using qualitative data analysis software (Atlas.ti).

Figure 1. Distribution of survey respondents



Understanding Self-Neglect

The concept of “self-neglect” is rarely applied to individuals under age 60 and is generally considered a geriatric phenomenon. Common characteristics categorized as elements of elder self-neglect, such as inadequate utilization of essential medical care, inadequate hygiene, unsafe living conditions (arising from excessive clutter and/or fire hazards), and refusal of services are generally defined differently for those under 60, or are referred to within the context of another descriptor, such as homelessness, mental illness, and/or substance abuse. As a geriatric phenomenon, self-neglect is generally subsumed within the broad category of elder abuse and neglect. There are many arguments that self-neglect is not a form of abuse and, as identified by the DAIL Self-Neglect Task Force (2012), “the immediate challenge with this classification is that with “self-neglect” there is no perpetrator and the classification does not fit the legal “perpetrator/victim” paradigm” (p. 4).

Despite being the most commonly reported form of elder abuse and neglect nationally, there is no unified, comprehensive definition for the concept of self-neglect. Medical and mental health practitioners have attempted to define self-neglect with specific diagnoses, including Diogenes Syndrome and now Hoarding Disorder as included in the Diagnostic and Statistical Manual of Mental Disorders (DSM) V (2013), but ultimately have failed to achieve consensus or incorporate the wide array of individual, social, and environmental factors often involved in self-neglect cases (Kutame, 2007; Brandl, Dyer, Heisler, Otto, Stiegel, & Thomas, 2006). Definitions of self-neglect are often laden with judgment-based principles and conceptualized solely through cultural and societal standards for self-care (Gibbons, Lauder, & Ludwick, 2006; Iris, Ridings, & Conrad, 2010). The apparent difficulty in defining self-neglect stems from both the ambiguous nature of the concept itself, as well as the limited research on the topic and a lack of consensus by national, state and local service providers. Further, although often vital for the provision of services, the connection of “self-neglect” to elder abuse and neglect may exacerbate the difficulty of defining and conceptualizing both the term and its response (Rathborn-McCuan & Fabian, 1992).

While there are no federal laws, rules, or regulations regarding the investigation and management of self-neglect reports, the 2006 amendments to the Older Americans Act (OAA) of 1965 provide the following definition of self-neglect:

“An adult’s inability, due to physical or mental impairment or diminished capacity, to perform essential self-care tasks including (A) obtaining essential food, clothing, shelter, and medical care; (B) obtaining goods and services necessary to maintain physical health, mental health, or general safety; or (C) managing one’s own financial affairs.”

On the state level, it is estimated that 13 states (including Vermont) do not explicitly include self-neglect within elder abuse and neglect statutes (Brandl et al., 2006). For those that do, definitions vary widely, including and excluding various clarifying elements such as the mental or physical capacity of the person considered to be self-neglecting, the presence and/or actions of a caregiver, and the severity of the impact of the self-neglect (Kutame, 2007; Rathborn-McCuan & Fabian, 1992). The use of these clarifiers not only speaks volumes to the complexity of defining self-neglect, but also provides an important level of consistency for local service providers.

Vermont's Definition

It is important to note that Vermont statute does not address the issue of self-neglect. Title 33, Chapter 69 addresses reports of abuse, neglect, and exploitation of vulnerable adults, but does not include self-neglect. In 1996, a Memorandum from Commissioner Patrick Flood mandated that referrals for cases of suspected self-neglect among those >60 be directed to the AAAs and those <60 be directed to Adult Protective Services (APS) (See Appendix A). It was also directed that APS would not provide case management, but would make referrals for such services. This position was restated in a 2005 communication from Commissioner Flood to State Senator Richard Sears, wherein he stated “For persons over 60, that case management properly belonged to the Area Agencies on Aging, which were already providing much of the case management. Unfortunately, there was no obvious party to provide those services for adults with physical disabilities under 60, so when those cases arise, APS is still directly involved” (See Appendix A). Ultimately, Vermont Statutes do not mention or make any prescriptions about self-neglect. A review of state definitions and jurisdictions for self-neglect indicates that Vermont is one of only four states where self-neglect does not fall under the purview of the state’s adult protective service system.

Members of the DAIL Self-Neglect Task Force, convened in 2012 to address the problem of effectively helping people identified as self-neglecting, expressed unanimous support for not recommending statutory requirements due to the sentiment that those engaging in self-neglect are in need of human services and support, not investigatory or legal approaches.

Establishing an effective response to self-neglect requires an understanding of how the concept is defined. The DAIL Self-Neglect Task Force (2012) adopted the OAA definition, with the addition of a clarifier.

“The term ‘self-neglect’ means an adult’s inability, due to physical or mental impairment or diminished capacity, to perform essential self-care tasks including (A) obtaining essential food, clothing, shelter, and medical care; (B) obtaining goods and services necessary to maintain physical health, mental health, or general safety; or (C) managing one’s own financial affairs. This definition excludes people who make a conscious and voluntary choice not to provide for certain basic needs as a matter of life style, personal preference or religious belief and who understand the consequences of their decision.”

While Vermont’s definition includes adults of all ages, this study revealed provider experiences and perspectives that parallel the national distinction of self-neglect as a geriatric phenomenon. Indeed, survey and interview responses indicate that the term “self-neglect” is generally not utilized for those under 60, but that the same characteristics or behaviors are categorized under the realm of another descriptor. As one participant noted, *“those people show up ... they’re not labeled as self-neglect, they’re labeled as having developmental issues, or mental health issues...substance abuse issues.”* Further, when asked to distinguish between the needs of and resources for those over and under 60, there were significantly fewer responses regarding those under 60. Some respondents indicated that they *“don’t have the experience with [the] under 60 population to make an informed response”* while others identified that there are *“no specific services for under 60 population, [they] fall into a crack.”*

Scope and Severity

The scope of self-neglect is particularly challenging to ascertain. Due to the aforementioned categorization of this issue as a geriatric syndrome, self-neglect estimates are generally embedded within estimates of the incidence and prevalence of elder abuse and neglect overall, which are considered to be underreported internationally and nationally. Further, states and localities have varying definitions of self-neglect and reporting processes, adding to the difficulty of obtaining clear numbers of confirmed cases and accurate estimates (Teaster, 2003).

While one of the study goals was to assess the scope of self-neglect in Vermont, it is extremely difficult to accurately estimate the number of individuals who could be described as self-neglecting, particularly those under age 60. When asked to estimate the number of cases they are involved in each year, the majority of survey respondents either did not respond or indicating they were *“unsure”* or *“don’t know.”* Survey responses indicate that providers are involved in an average of 23 cases involving older adults (60+) and 10 cases involving adults under 60 each year. However, estimates ranged significantly from 0 – 300, and there is no way of assessing how many of the cases are duplicative across sites and providers. Significantly

varying estimates and missing data make this data difficult to interpret and should be evaluated cautiously.

From April through November 2013, APS received 78 self-neglect reports for people 60 or older. APS does not currently track the number of self-neglect reports for individuals under 60. In Vermont, APS and AAA data can provide some indication as to the extent of reports and referrals, however the apparent confusion about where to make reports/referrals (see forthcoming section on responding to self-neglect), variations in parties responsible for follow-up on a referral (APS for <60 and AAA for >60), and lack of a specific “self-neglect” assessment category in the AAA data system results in concerns as to the soundness of existing data. The need for definitional clarity, more accurate reporting of self-neglect, and consistent documentation is not only important for the development and provision of services, but vital to the health and well-being of those involved.

Warning Signs and Symptoms

Though many studies have shed light on potential risk factors and causes for self-neglect, it is still unclear exactly how these aspects inform, influence, and compound one another to cause and perpetuate self-neglect. Study respondents identified the frequency of common warning signs and symptoms in suspected cases of self-neglect for those <60 and for those 60+. Warning signs and symptoms included inadequate nutrition, inadequate hygiene, inadequate or inappropriate clothing, inadequate home appliances and utilities, inadequate living conditions, inadequate management of financial affairs, inadequate utilization of necessary medical care, inadequate utilization of other services to maintain health and safety, and abuse, neglect or exploitation by others.

Figures 2 and 3 illustrate the perceived frequency of warning signs and symptoms for those under 60 and 60+. For both those under 60 and over 60, the most common warning signs reported were inadequate living conditions and inadequate basic hygiene, while the least common was inadequate home appliances and utilities. Inadequate nutrition, inadequate management of financial affairs, and abuse, neglect, or exploitation by others were noted as frequent warning signs much more often for those over 60. It is important to note that just over half of the participants (55%) responded to the questions regarding warning signs and symptoms for those under 60 (on average 75 responses per item), while 75% responded to the questions related to those over 60 (on average 102 responses per item).

Figure 2. Frequency of Warning Signs and Symptoms: Under 60

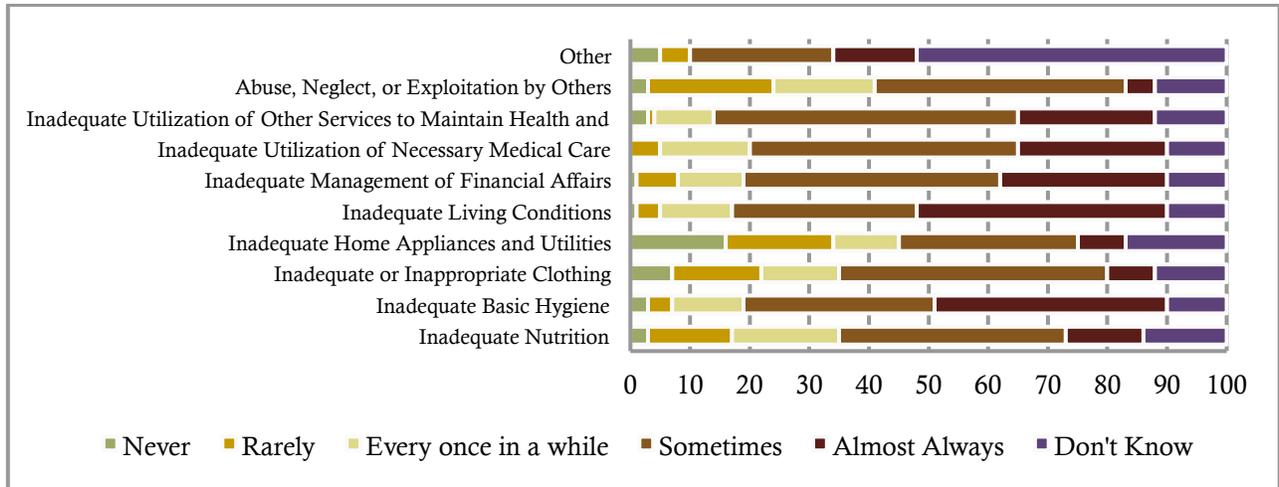
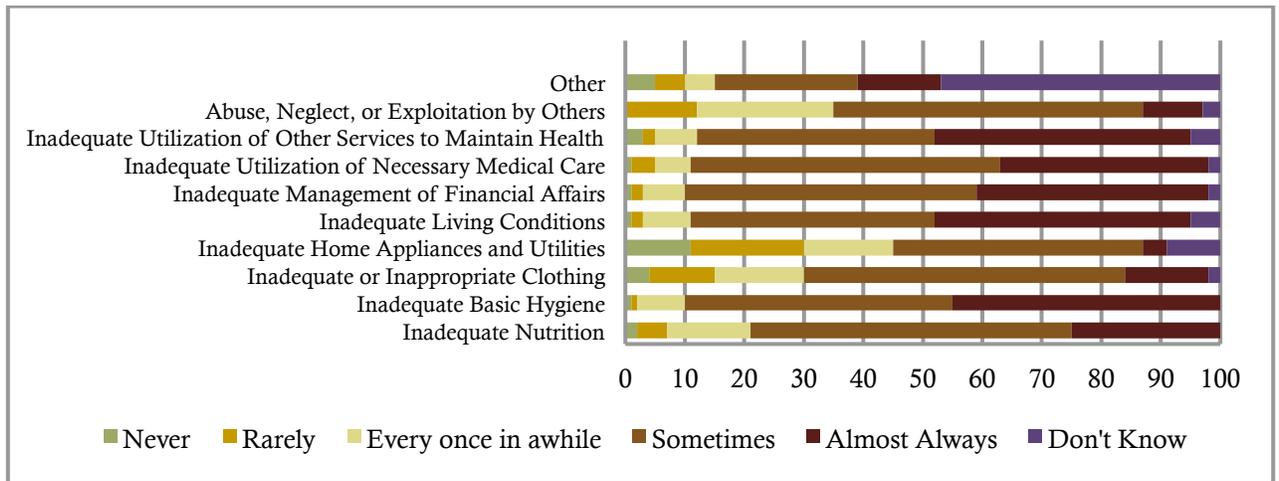


Figure 3. Frequency of Warning Signs and Symptoms: 60 and Over



In addition to sharing their perceptions about the frequency of the specific warning signs listed above, the majority of respondents (59%) either strongly agreed (13%) or agreed (46%) that “individuals identified as ‘self—neglecting’ usually have underlying, untreated mental health problems or cognitive impairment.” There is indication that many providers are unsure, as 28% neither agreed nor disagreed with this statement. Mental health issues and cognitive impairment are among the most commonly cited causes or risk factors for self-neglect, and weigh heavily on discussions of capacity and competence. Those who self-neglect are likely to have some form of mental illness or cognitive impairment (Brandl et al., 2006), with dementia and depressive symptoms being the most common (Dyer, Pavlik, & Murphy, 2000; Abrams, Lachs, & McAvay, 2002; Bartley, Knight, O’Neill, & O’Brien, 2011; Burnett et al., 2006). Likewise, cognitive impairment and declines in executive functioning are often found in conjunction with self-neglect (Abrams et al., 2002; Dong, Simon, Fulmer, Mendes de Leon, Rajan, & Evans, 2010). In addition to mental health issues and impaired cognitive

functioning, physical illness, alcohol use, and limited social supports have all been discussed as primary indicators and causes for self-neglect; but it is often a combination of these factors, as well as additional aspects, that indicate a high potential for self-neglect. Nerenberg (2008) also poses that self-neglect is a symptom of trauma, with major events acting as turning points towards self-neglecting behavior. Additionally, a history of abuse of domestic violence has been identified in self-neglecting elders (Bozinovski, 2000). While it can be helpful to acknowledge potential causes, common warning signs and symptoms, one participant clearly articulates the importance of individualized assessment and response:

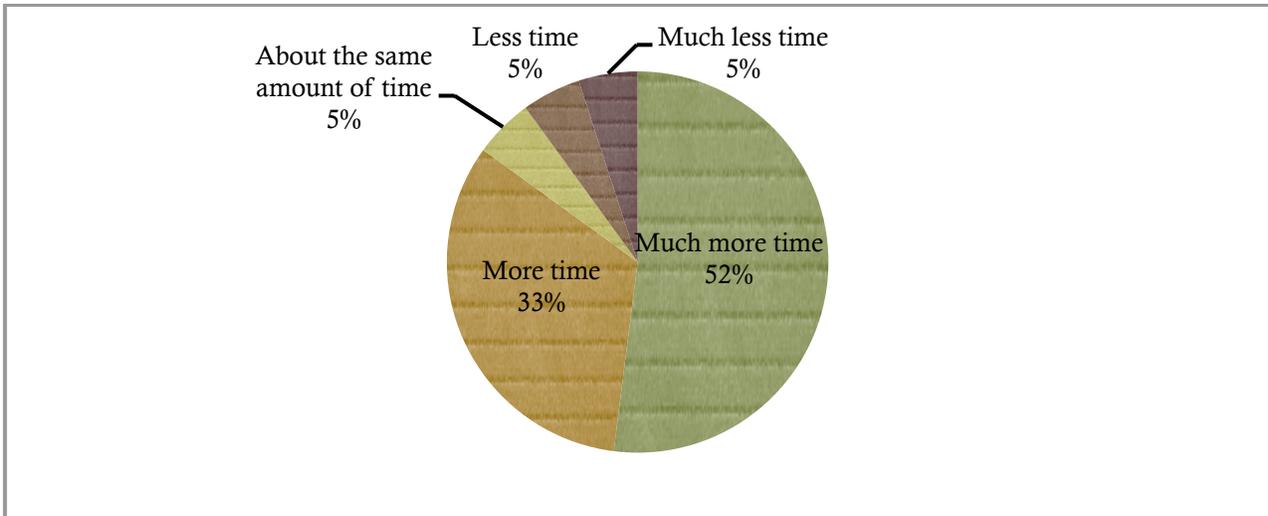
“Although most self-neglect cases have common denominators, each case is unique to the individual involved and there can not be a blanket “formula” to address the needs of these unique folks who come to our attention.”

It is important to note that several study participants noted the role of economics in our identification and categorization of self-neglect. As one respondent noted, “*wealth can buy you a lot of leeway, so people who are self-neglecting who are really wealthy are just seen as eccentric.*” This raises some important questions about the role of poverty in self-neglect identification and intervention.

Responding to Self Neglect

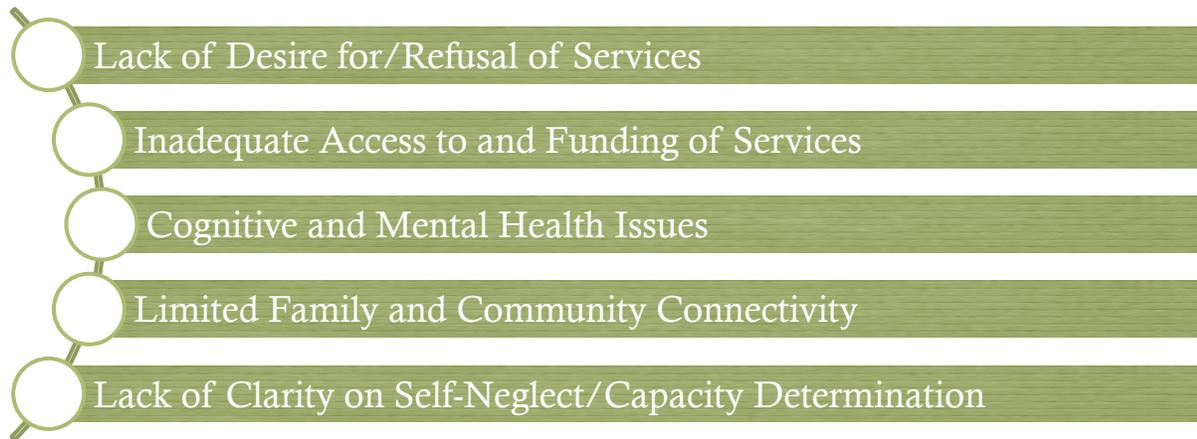
As a result of the complex combination of contributing factors and challenges in assessment (i.e., invisibility and/or isolation of individuals suspected of self-neglecting, assessment of decision-making capacity), service providers overwhelmingly report that compared with the average workload, cases of self-neglect take more time. This is in part due to the amount of time invested in engagement and relationship development, particularly given that many individuals considered to be self-neglecting are not receiving or interested in receiving services. Self-neglect cases are also time consuming due to the crisis-oriented nature of such cases. One participant commented, “*self-neglect is just that, a crisis waiting to happen most of the time and that’s when change will happen or could happen*” and several referred to the cyclical nature of such cases, where a crisis is abated and there is a lull until the next anticipated crisis occurs. Another element of the time-intensive nature of self-neglect cases is the “psychic time” invested due to the emotional elements and common ethical dilemmas experienced. As indicated in Figure 4, 52% report that cases of self-neglect take much more time and 33% report they take more time. The remaining 15% of providers report that cases of self-neglect take about the same amount of time (5%), less time (5%), or much less time (5%).

Figure 4. Time Spent on Self-Neglect Cases Compared to Average Workload



In addition to the extensive amount of time that is spent on cases of self-neglect, providers identified a number of key challenges to serving adults who are self neglecting (See Figure 5).

Figure 5. Greatest Challenges to Serving Adults Who Are Self-Neglecting



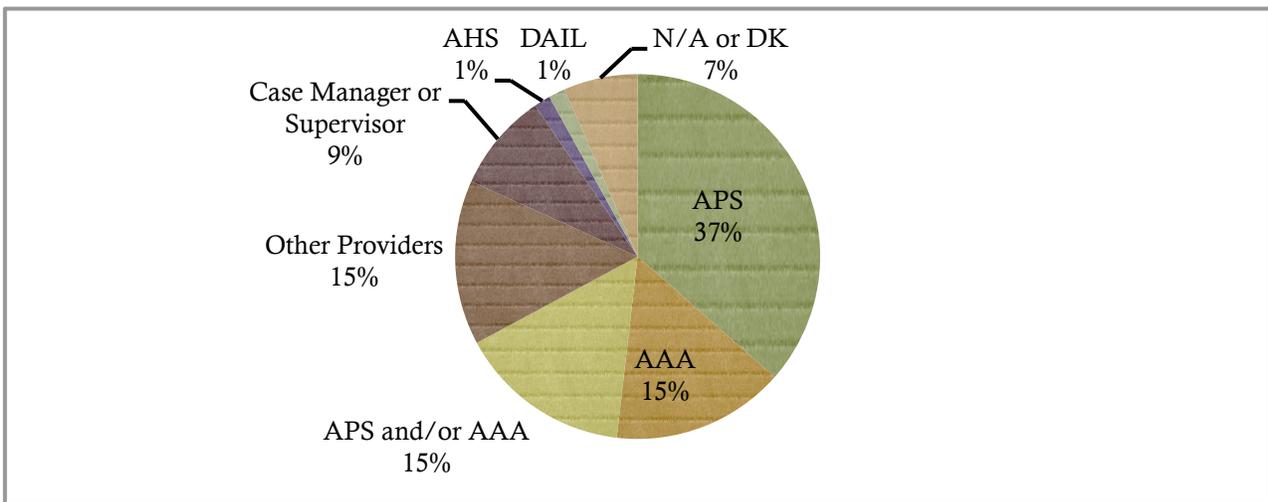
These challenges are inherently and intimately connected to the current response to cases of suspected self-neglect, and inform recommendations for enhancing a coordinated community response through a combination of **1) training and education, 2) outreach, assessment, and service provision, and 3) enhanced community support and involvement.**

Training and Education

One of the central challenges of responding to self-neglect is a lack of clarity about what self-neglect entails and where to make referrals. Study findings clearly indicate a lack of clarity regarding self-neglect reporting. Providers are reporting cases of self-neglect to a wide variety of organizations, programs, and providers, as illustrated in Figure 6. Providers most

commonly report to Adult Protective Services (APS) (37%), with 15% of respondents reporting to the Area Agency on Aging (AAA), and an equal number (15%) noting that they make reports to APS *and/or* the Area Agency on Aging (AAA). Those making reports to both may be doing so because they are reporting suspected cases for those under 60 (to APS) *and* over 60 (to AAA), because cases of elder self-neglect reported to the AAA may present with suspected concurrent abuse or neglect by a perpetrator reported to APS, or because the reporting/referral process is unclear and/or inconsistent. Given that the majority of reported cases of self-neglect involve individuals >60, the majority of reports should be made to AAAs, if reporters are clear as to the reporting/referral process.

Figure 6. Where Providers Report Suspected Self-Neglect



Respondent comments reflect the potential complexity of these situations, as well as confusion about where reports should be made. One clearly stated, “*I don’t know where to report this*” and another commented that “*most go unreported unless life threatening.*” Further, the challenge in reporting cases of self-neglect for those under 60 was highlighted: “*For people 60 or older, reports are made to the Area Agency on Aging providing services in the region where the person who is self-neglecting resides. For persons under 60 years old, referrals may vary. There is no one place/source to make a referral for self-neglecting younger adults.*” The suggestion was made to address this issue by providing a single point of entry: “*A single point of entry would help curb some of the community confusion and allow that agency to help clients while educating the community about the greater issues.*” However, it was acknowledged that regardless of age, it is a challenge that “*there is no mandate to intervene in cases of self-neglect...so if someone refuses treatment no follow up occurs.*”

In addition to clarifying what self-neglect is and how/where it should be reported or referred, participants expressed a strong need for specialized training and education about how to respond in cases of self-neglect, with the majority of respondents in all areas of the state agreeing that it is important to have “*training on self-neglect.*” It was noted that this training is

needed “*across the continuum of health care providers.*” As identified in the forthcoming section on services, participants articulated a need for trained providers to conduct assessments for self-neglect, particularly in terms of assessing decision-making capacity, mental health and cognitive impairment. Further, many frontline providers acknowledged that responding to cases of self-neglect requires unique expertise in establishing trust, building rapport, respecting self-determination and assessing risk and capacity. While many providers “*really want to help,*” they often need training and resources to do so.

RECOMMENDATIONS

There are several areas where training and education could significantly enhance the response to self-neglect.

➤ **Clarity around the reporting and referral process for suspected cases of self-neglect.**

It is possible that this process may benefit from review and modification to establish a single point of entry and reflect the most appropriate location for coordinating the response to cases of self-neglect. Clarification of the reporting and referral process is fundamental to an effective response to self-neglect.

➤ **Service providers across the continuum of health and social services are in need of training to help recognize self-neglect and make appropriate referrals.**

Nearly 75% of respondents reported that training on self-neglect was an extremely important component of responding to self-neglect. Training and education will be a valuable next step in ensuring accurate reporting and adequate response in cases of self-neglect.



➤ **Public education to help raise awareness about warning signs, resources and referral options.**

Not only did providers express a need for more training and education for themselves, but for families and community members as well, given the role of community concern and involvement in reporting/referring suspected cases of self-neglect. Of particular concern is raising public awareness regarding self-determination and the limits to intervention.

Services

Given that one of the defining features of self-neglect is the failure to obtain goods and services necessary to maintain health and safety, those considered to be “self-neglecting” rarely present for services. Thus, outreach and engagement are essential for assessment and service

provision. Through outreach efforts and adequate time invested in establishing trust, service providers can assess for self-neglect and either provide or connect individuals to essential case management and health/mental health services as appropriate. As one participant noted, “*One size doesn't fit all. Each case needs to be individually assessed.*” One of the challenges in responding to cases of self-neglect is the extensive time often necessary for relationship development before an individual is open to services. In a time of limited resources, this level of outreach and engagement may not be feasible due to competing demands, or when provided may result in a disruption of services to other clients. Many respondents highlighted the importance yet time intensive nature of building rapport:

Building relationships that enable change takes time and repeat visits...often with little visible sign of success.”

In addition, several respondents noted the cyclical nature of many self-neglect cases, commenting on the challenge that “*even if this behavior is identified and addressed, it will most likely resurface.*” This points to the time and effort intensity of such cases over time and the need for what one provider called “*perseverance,*” and another referred to as “*consistent presence and compassion.*”

Assessment of Self-Neglect

Currently, there are few accurate or official measurements for the assessment of self-neglect. This is due in part to the lack of a universal definition and the limited research on effective self-neglect assessment tools (Kelly, Dyer, Pavlik, Doody, & Jogerst, 2008; Brandl et al., 2006). Most commonly, individual judgments of APS field workers, AAA case managers or health professionals are used to initially determine cases of self-neglect. Psychiatric interviews, KELS, and VES-13 tests may be used to determine capacity and assess ability to perform activities of daily living, but none are formatted for field use and often require specialized testing tools and personnel (Burnett, 2006). Specific assessment tools for hoarding behaviors have been suggested for use, however they tend to focus heavily on environmental elements and may not adequately assess for the physical, social, or psychological elements of self-neglect.

One of the most useful tools currently available is the Self-Neglect Severity Scale (SSS), recently developed by the Consortium for Research in Elder Self-neglect of Texas (CREST) in response to the limited options for field assessments of self-neglect (Kelly et al., 2008). Developed from interviews with APS workers and a national expert panel, the SSS assesses the hygiene, functioning, and environment of individuals through observational ratings of trained observers. Field tests have shown it to be both reliable and effective, but it is somewhat extensive for practical field use, still based on observer judgment, and unclear whether it needs to be used independently or with additional assessment tools (Kelly et al., 2008).

Approximately 68% of study respondents indicated that they (or their organization) conduct an assessment of self-neglect. Assessment of self-neglect appears to be happening in a myriad of ways, frequently on an informal, observational basis. Specific tools identified include several references to a “self-neglect assessment tool”, the “Independent Living Assessment (ILA)” and an “Activities of Daily Living (ADL) checklist.” It was repeatedly acknowledged that an essential part of assessment is a home visit or opportunity to observe the individual in their home environment. One participant noted, “*We do not have a formal system to assess self-neglect, however I am in their homes on a regular basis and we can see [the warning signs]. I would not see it if they were coming to my office for appointments.*”

There remain significant questions about who is assessing for self-neglect and what that assessment involves. Of particular importance is the assessment of physical or mental impairment or diminished capacity, such that the individual is not making a conscious and voluntary choice and/or does not understand the consequences of their decision. While there were several indications of assessment of cognitive ability or decision-making capacity, it is unclear who is conducting such an assessment, and how. While some respondents indicated they were comfortable conducting this type of assessment and consulting with mental health providers in questionable or challenging cases, others indicated that they felt this type of assessment was beyond the scope of their roles and responsibilities. Only one survey respondent noted the use of a specific tool for assessing for cognitive impairment, the Mini-Mental Status Examination (MMSE). Given the fundamental role of diminished capacity in the definition and identification of self-neglect, this is an essential area to address.

The refusal of service is often an important and complicating factor of self-neglect. Study participants identified this as the greatest challenge to serving adults considered to be self-neglecting. This is particularly challenging for AAA case managers, who have a designated expectation to respect and promote older adult clients’ right to dignity and self-determination. Frontline responders are often in the center of the inherent conflict between society’s desire to protect vulnerable adults from harm and respect for individual autonomy (Mixon, 1991). An essential element of cases where services are refused is deciding whether someone has the capacity to make that decision. Determining capacity and competence are extremely difficult tasks, and often prove to be a “grey area” for most practitioners, who have very few specific guidelines for such determinations. One of the biggest difficulties for practitioners is that they often lack the tools or resources to determine capacity. Capacity determinations can, usually, only officially be made by a geriatrician or psychiatrist (Day, 2010), which often requires an office visit. For individuals who are homebound or wary of office visits, obtaining an official determination can prove difficult. Additionally, balancing respect for self-determination with

both a desire for individual well-being and legal or organizational requirements can lead practitioners into an ethical quandary (Gunstone, 2003). Indeed, the vast majority of respondents (90%) strongly agreed (41%) or agreed (49%) “self-neglect cases inherently present ethical challenges/dilemmas.” The ethical challenges center mostly around the issue of self-determination, with participants articulated a range of concerns on both ends of the spectrum such as “*we too often use the right to self-determination to excuse our doing nothing*” and “*no one seems to remember the parts of that language that says ‘due to diminished capacity.’*” Indeed, the multi-layered nature of capacity and the significant implications of capacity determination demand adequate resources for assessment.

Case Management

Case management services are consistently identified as an essential component of the response to cases of suspected self-neglect. Due to the complex nature of contributing factors, case managers play an important role in establishing trusting relationships, connecting individuals to valuable services, coordinating care, and facilitating inter-professional, interagency collaboration. Unfortunately, study respondents expressed significant concern about the “*lack of funds to support the time and staff needed to provide adequate case management*” and a need for additional resources to support the mandated responsibility for responding to cases of suspected self-neglect. Further, participants indicate that while case management services are generally available and accessible for older adults, they are more limited, or in some cases “*virtually non-existent*” for those under 60.

Given the challenge of ambivalence toward services and the time-intensive nature of cases of self-neglect, it is essential that service providers build rapport and establish trust with potential clients or service users. Often this requires repeated outreach and home visits, which can be challenging to provide within the context of current economic pressures and resource limitations. Indeed, if case managers are to coordinate vital services to support the physical health, mental health, and/or general safety of clients, the first step is a foundation of trust, which can take time to establish with individuals who initially refuse services and often, “*don’t want to be rescued.*” Further exacerbating the difficulties of service refusal, larger issues of funding, quality, and access of services impact why individuals may refuse services. Individuals may refuse service for legitimate reasons such as poor prior experience with service providers, low quality, and/or barriers to access. One of the most commonly noted challenges in responding to cases of self-neglect was a lack of access to and funding for services and concern that “*programs are cut even as the demand grows.*”

Case managers play a crucial role in coordinating care and facilitating collaboration. Often, responses to cases of self-neglect involve the AAA, APS, and other social service or aging

service providers. Many study participants articulated a desire for increased involvement from town health officers, animal control, and zoning authorities, as well as family members and community faith-based organizations. Nearly 95% of survey respondents reported it is important to engage in interdisciplinary collaboration with colleagues and providers from other organizations. The following participant comment articulates the need for such collaboration:

Individuals “respond uniquely to different types of intervention; someone might take the animal control officer’s recommendation very differently than one with the same ends by the town health officer. For this reason, self-neglect needs to be approached in a customized way which requires collaboration across a variety of sectors.”

Mental Health and Cognitive Function

As previously discussed, issues of mental health issues and cognitive function are among the most commonly cited causes or risk factors for self-neglect, and weigh heavily on discussions of capacity and competence. While the majority of respondents (59%) either strongly agreed (13%) or agreed (46%) that “individuals identified as ‘self—neglecting’ usually have underlying, untreated mental health problems or cognitive impairment,” there is widespread concern that “*there is a serious lack of mental health services, and those we do have are not always easily accessible to the people who need them.*” Another fundamental concern is the role of dementia and cognitive impairment. One participant noted that the definition of self-neglect is “*in a nutshell, what happens to somebody who has dementia...because it is by virtue of the disease process and trajectory going to happen if someone does not step in.*”

Interestingly, while case management services are perceived to be more readily available for older adults, mental health services are perceived to be more readily available for those under age 60. In general, many survey respondents indicated a perception that mental health issues were more common for those under age 60, while cognitive impairment was more likely to be involved for those over 60. Regardless, however, the need for mental health services and the involvement of mental health professionals in suspected cases of self-neglect is vital. Study participants articulated a need for mental health professionals in terms of both determining capacity and helping to address issues underlying the presenting concern of self-neglect.

It was repeatedly suggested that there is a fundamental need for greater collaboration among case management, mental health services, and others. Many respondents identified a need for collaborative outreach and assessment, and specifically noted the prerequisite of adequate funding of mental health services and availability of geriatric mental health providers in particular. Accessibility of mental health services was noted frequently, indicating that there is a need for “*more accessible mental health services and supports which are not only office based but*

community based” and “more access to mental health information, services and support for self-neglect clients and the community partners who need guidance in how to help them.” While the elder care clinician program was frequently highlighted as a valuable resource, it seems as though there is significant variability in accessibility and utilization throughout the state. Concerns were raised regarding inadequate funding of this program, inaccessibility to providers due to long wait lists or inability to respond to crisis situations. Several respondents noted concerns that mental health providers were unwilling or unable to address co-occurring mental health issues and cognitive impairment, and that there is a serious need for mental health providers, particularly emergency/crisis responders who can adequately conduct differential diagnostic assessment.

It is important to note that substance abuse was also acknowledged as a potential cause or contributing factor in cases of self-neglect. Based on both survey and interview data, issues of substance abuse are often included in discussions of mental health and may not be adequately captured as a unique factor. Further, study participants indicated that substance abuse treatment, particularly for older adults, is extremely limited and thus may not have been included as frequently as an important element of the response to self-neglect cases. The role and extent of substance use in cases of self-neglect is unclear and would be an important area for further investigation. Until more information is known, it would be beneficial for providers responding to suspected cases of self-neglect to include screening and referral as appropriate.

RECOMMENDATIONS

Of primary importance is *recognition of the essential services provided in the current response to the issue of self-neglect*. Those currently on the frontlines of response face a challenging situation in engaging individuals who frequently do not desire involvement with formal service providers, and in working on high risk, high demand cases with diminishing resources.

There are several services essential for an effective response to self-neglect.

➤ **Resources to Support Outreach and Assessment.** Enhancing the response to self-neglect requires sufficient resources to ensure adequate outreach and assessment. While this may require resources at the front end, it could help to distinguish between those cases that qualify as self-neglect or not, so that services can be referred and coordinated most appropriately and efficiently. This could help to avoid allocation of provider time and resources to inaccurately categorized cases/situations, thereby potentially reducing costs in the long term.

➤ **Case Management and Mental Health Services.** Based on participant feedback, there is a significant need for case management services for those under 60 and mental health

services for those over 60. Case managers and mental health providers play a crucial role in the response to self-neglect and require adequate funding to ensure they are available and accessible to those in need. An oft-cited concern noted by respondents was that once an individual was open to receiving services, there is the challenge of categorical requirement when “*what we really need are flexible resources.*”

“Each situation is unique and that needs to be kept in mind when creating a training protocol or system to address this issue. There needs to be a great amount of flexibility given to the agency who is going to work with this population.”



Both case management and mental health providers require *specialized training and/or access to expertise via consultation* when responding to cases of self-neglect. Several respondents indicated a desire for designated staff to respond to self-neglect cases. While some indicated a preference for a specially trained and/or experienced staff to be hired/assigned to address self-neglect cases, given the high need and expectations for engagement and unique characteristics of these cases, others suggested having all staff trained and/or having a specialist available for consultation so that all staff are able to respond accordingly. Another

option is teaming case managers and mental health providers together to respond. Ultimately, there is significant need for expertise in this area and resources to support the provision of specialized services for self-neglect cases. Case studies from across the state (Appendix B) highlight the complexity of self-neglect cases and resulting need for distinct skills.

Self-neglect is often very grey. Frequently the person who is self-neglecting in our eyes doesn't think there is a problem. Developing the necessary skills to meet the person on their own turf, and help them through the situation is essential. Approaching with respect, understanding what it is the person may want or need, is essential and often may not jive with what his/her family or community find acceptable. There are no quick fixes, and it is not easy to know what the 'right thing' is, or to avoid placing our own values on the person/the choices they've made...Figuring out what can be done, should be done, what the individual wants or will accept, is not an easy task.

There are some promising models of interagency collaboration in the state, such as the Northeast Kingdom Vulnerable Adult Action Coalition (NEKVAAC), made up of a team of

local law enforcement, social service and health care providers dedicated to insuring the safety and well-being of vulnerable adults. Whether through existing teams and collaborative meetings, the development of new partnerships, or individual provider relationships, it is clear that inter-professional, interagency collaboration is essential to accessing expertise, maximizing resources, and providing a comprehensive response to self-neglect.

You want a system so there's some equity and some resource for response but you also don't want it to be so structured and bureaucratic that you can't hear each story and deal with it as needed.

Community Engagement

Generally, cases of suspected self-neglect come to the attention of service providers following a report or referral by concerned family, community members, or providers. While this often reflects a value of community and care for fellow community members, it also raises important questions and concerns reflected in the spectrum of perspectives regarding the role of personal choice and the balance of safety and risk. For instance, while the majority of survey respondents strongly agreed (12%) or agreed (43%) “individuals of all ages should be able to do what they wish with their lives and their property” there are many who neither agree nor disagree (31%). This reflects the potential limits to personal choice perceived by some providers and community members. The following provider comments illustrate the range of expectations regarding community involvement and impact.

“More community empathy for folks who may be different. Less judgmental attitude to folks who are different.”

“For many people it is a long-standing habit and lifestyle. It should not be tolerated because it adversely affects the entire community.”

Several provider respondents indicated that the values and concerns of community members can be difficult to manage, particular in addition to the challenges of their daily work. For instance, providers may spend “a lot of time spent listening to community members’ concerns...getting yelled at by community members that “no one is helping” the person” or “dealing with other agencies and individuals calling about the client [asking] why aren't you doing something? Without understanding issues around working with someone who is self-neglecting.” Participants, particularly those on the frontlines of responding to self-neglect cases, expressed the difficulty of being on the receiving end of frustrations and helping other service providers and community members understand the nature of confidentiality and the limits of intervention.

Limited family and/or community connectivity was cited as one of the top challenges in cases of suspected self-neglect. There were several indications that families are not adequately included in the response to self-neglect, however this may be due in part to existing or concern about concurrent abuse and neglect by a family member or caregiver. Others referred to either a lack of support *from* family members to the self-neglecting individual and/or a lack of support *for* family members caring for the self-neglecting individual. The impact of dementia and cognitive impairment, and the resulting demands placed on family caregivers, cannot be underestimated. While the “*possibility of neglect blossoms*” when an individual has dementia, there is a simultaneous concern that the heavy reliance on family care is “*physically, emotionally draining for family which then leads to self-neglect of the caregiver, and potentially neglect of the person with dementia.*” Overall, many study participants reflected the sentiment that there is a significant need for providing family support and establishing a network of community volunteers to help when needed.

“It is an issue that impacts not only the individual and their family but the community as a whole. If we can find ways to assist individuals with the underlying causes of self-neglect we will enhance the overall health and well-being of all.”

Study participants offered several innovative strategies for a true community-based response to self-neglect, including community spaces, outreach, and the utilization of peer support networks consisting of volunteers and senior companions. It was suggested that we “*need to have spaces in the community that are safe, community centered spaces that are open cradle to grave.*” Local communities might “*lead the community in frank discussions about the ethics and realities of those who might be self-neglecting and educate [about] available resources*” and/or “*establish strong volunteer networks for home visits and local companions.*” However, some respondents also noted the challenge of “*getting community partners or members to participate in helping the self-neglecting person.*”

Several respondents indicated that since the nature of self-neglect cases is that people “*don’t want services*” it is important to provide information and options via volunteers or a peer support network. However, some were clear that it would be important to utilize paid peers rather than unpaid volunteers, due to the nature of the work. Also, several expressed significant concern that such a model would require extensive training, as well as ongoing support and supervision. It was noted that some individuals might be open to informal peer support – but perhaps only from a known neighbor or true peer (i.e., farmer to farmer), but might react negatively to perceived intervention via a network of community volunteers representing local teens, business people, or town leaders.

RECOMMENDATIONS

Given the role of concerned community members in bringing suspected cases of self-neglect to the attention of providers, there are several ways that community support and involvement could enhance the response to self-neglect.

- **It is of primary importance that the public is informed regarding the nature of self-neglect and process for report, referrals, and response.**

Related to the recommendation provided under training and education, a public awareness campaign may be useful in providing this information and education to the broader Vermont community. Such efforts may already be underway in some areas of the state.



- **There is a clear need for additional support for families and caregivers,** specifically of individuals suspected to be self-neglecting. Of particular concern and worth further investigation is the issue of caregivers who may be neglecting to address their own needs in the process of caring for a loved one. As long-term care services are increasingly home and community-based, family caregivers will likely need additional supports to help reduce cases of self-neglect as well as potential abuse and neglect resulting from caregiver stress.

- **Community Involvement.** Ultimately, the movement toward a coordinated community response to self-neglect could be strengthened by an effort to involve community members through an organized volunteer/peer/companion network. As community members are generally the concerned party that brings self-neglect to the attention to others, they may be well positioned to be an active part of the response. Providers can partner with communities to engage in both prevention and intervention efforts, however it is clear that significant attention to and resources for training and support would be essential to success.

Conclusion

In summary, there are several central recommendations for creating a coordinated community response to the issue of self-neglect. Figure 7 outlines potential steps in responding to self-neglect via a combination of **1) training and education, 2) outreach, assessment, and service provision, and 3) enhanced community support and involvement.**

Figure 7. Recommendations for Responding to Self-Neglect in Vermont

	First Step	Next Step	Areas for Future Exploration
Education	<ul style="list-style-type: none"> Clarify existing reporting requirements/expectations 	<ul style="list-style-type: none"> Provide training for providers Plan public awareness campaign 	<ul style="list-style-type: none"> Provide additional support and funding for AAAs Designate single point of entry
Services	<ul style="list-style-type: none"> Provide adequate funding/support for outreach services Establish process for assessment - involving collaboration, particularly of case management and mental health 	<ul style="list-style-type: none"> Provide adequate funding of case management and mental health services Establish strategy for collaboration in self-neglect cases 	<ul style="list-style-type: none"> Expand case management services for under 60 Expand mental health and substance abuse services Streamline interagency collaboration efforts across high need/high risk cases
Community Involvement	<ul style="list-style-type: none"> Implement public awareness campaign to improve reporting/referral process 	<ul style="list-style-type: none"> Enhance support for families and caregivers Develop trained peer/community network 	<ul style="list-style-type: none"> Enhance collaborative prevention efforts to support individuals, families, communities

While the aforementioned recommendations are likely to enhance the response to self-neglect, there are foundational matters to consider as well. Ultimately, further consideration of use of the term self-neglect as well as the location of its response is highly recommended. In some ways, the terms itself is problematic. If a person is not cognizant that they are neglecting their own self-care, due to diminished capacity, can it really be considered “self-neglect?” As illustrated above, the term is generally reserved for older adults, despite the fact that difficulty performing essential self-care tasks is certainly not restricted to certain age groups. This raises some important questions about how and why this comes to be an age-related issue to be addressed by the aging services network. Further, by definition “self-neglect” is due to physical or mental impairment or diminished capacity. If this is the case, it is possible that the secondary categorization of “self-neglect” is simply a symptom of a primary issue of concern (i.e., mental health, cognitive impairment). As such, it seems imperative that systems of care addressing underlying issues are actively involved in responding to cases of self-neglect. While the aging service network (most notably AAAs) provide essential care and response in cases of self-neglect, and have a fundamental role in supporting the overall health and well-being of older adults and caregivers, the definition of self-neglect indicates that systems of care involved

in addressing the physical or mental impairment, or diminished capacity, should be active collaborative partners, not peripheral responders.

In a time of financial constraints and increasingly limited resources, service agencies and providers face challenges to collaboration, including time and competition. Many study participants acknowledged that while collaboration is key to an effective response to self-neglect, there is limited time for additional team meetings. Local areas may prefer to utilize existing interagency meetings or collaborate on a one-on-one, case-by-case basis. It was also noted that while agencies need to work together, and often have a long history of doing so, they are simultaneously vying for limited resources, creating a competitive rather than collaborative environment.

“There are a lot of really great organizations out there who are doing good work, but it doesn’t seem to be enough. I think we need better collaboration and a clearer division of labor so the community knows who to call about a specific situation. If there is more team work, and greater understanding among professionals about what we are all supposed to be doing, we can accomplish a lot more with our current resources.”

In addition to an amplified need for innovative, inter-professional and interagency collaboration, Vermont faces unprecedented social and economic challenges due to the aging of the population. Vermont is currently the second oldest state in the nation and it is expected that by 2030 one out of every four Vermonters will be over the age of 65 (U.S. Census, 2011). Along with Vermont’s shortage of primary care physicians, several participants raised serious concerns regarding the already limited number of geriatricians, neurologists, and geriatric-trained mental health and substance abuse providers. As one participant noted, *“there has to be a huge increase, to meet the need coming down the road.”* Given the aforementioned categorization of self-neglect as a geriatric phenomenon, it is likely that such cases will be on the rise. As a result, *“we have to start coming up with models of ways to care for our seniors in a different way.”*

Vermont has a well-established history and reputation of honoring independence and self-determination. As one participant noted, *“we live in a culture in Vermont where people can pretty much do what they want to do as long as they’re not hurting someone else.”* In light of the Vermont *“tradition of being independent...that kind of Yankee ingenuity, “I can do it myself;”* providers responding to self-neglect cases will face the inherent dilemma of respecting an individual’s right to self-determination while fulfilling the societal duty to protect. Ultimately, an effective coordinated community response to self-neglect will require innovation, collaboration, and renewed commitment for *“reducing the risk or possible harm”* for all community members.

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Appendix A

SELF-NEGLECT REPORTING MEMO (1996)



Laine, Dagny, 4-11-96

D.L.P.

State of Vermont

DEC 19 1996
AGENCY OF HUMAN SERVICES

DEPARTMENT OF AGING AND DISABILITIES

Division of Advocacy and Independent Living
103 South Main Street
Waterbury, Vermont 05671-2301
<http://www.state.vt.us/dad>
(802) 241-2400 (Voice/TDD)
Fax (802) 241-2325

MEMORANDUM

TO: HHA Executive Directors
FROM: Patrick Flood
DATE: December 13, 1996
SUBJECT: "Self Neglect" Reporting

AUG 21 2002

A couple of questions have arisen regarding the reporting of so-called "self-neglect" cases, so I want to reiterate the current policy. I have attached a memo we sent back in October which announced the change.

Please share the October 14 memo with appropriate staff. There is no need to report self neglect cases to APS; your staff are not mandated reporters for such cases. Of course, they remain mandated reporters for cases when abuse, neglect or exploitation is being perpetrated by someone upon an elderly or disabled adult, and if you have any questions about your duties with regard to those cases, please contact Dagny Reimondi.

Our belief is that self neglect cases require services more than an investigation, and that most often intensive case management or guardianship is really the key to successfully addressing the concerns.

Behind most reports of self neglect is a genuine concern for the client who is viewed as at risk. In some cases, the client is quite mentally impaired; in others, it is not so clear. We recognize the complexity of many of these situations and have begun a discussion with the Vermont Ethics Network about how the issue of assuming or negotiating risk can be best addressed. Hopefully in the ensuing months we will be meeting with communities to talk about the most appropriate and successful ways to address these concerns.

Please call me if you have any questions about this memo.

cc: AAA Directors

Appendix B

SELF-NEGLECT CASE EXAMPLE A

Joe is a 73 year-old man living independently in rural Vermont. He was originally referred by the Senior Helpline who received a request for help from a discharge planner at a nearby hospital. Joe had been recently admitted to the hospital with poorly controlled blood sugar and related complications. The discharge planner called to say that Joe had lost his Economic Services benefits for failing to complete an annual renewal so the goal was to help him fill out a new application.

An immediate problem in working with Joe was the challenge of initial contact, since it took several attempts to locate him. He would not answer his phone and rarely could be found at his apartment. He is known in the community for a long-standing habit of walking the streets and taking “stuff” home to his apartment. The case manager made multiple attempts to contact Joe by driving around town checking out different places known to be favorite stopping places for him. Joe was finally located following one of many calls to his sister who lived next door when she informed the case manager that he was at the doctor’s office. The case manager immediately drove to his doctor’s office and waited about an hour until she was able to meet with him.

At the time of the initial visit from the case manager, Joe was living in subsidized housing and receiving help from the VNA to manage his medications and insulin. However, the issue of him never being home posed a problem for the VNA because they could not be always pursuing him. They ended up stopping their visits after several attempts and eventually the housing property management contacted the case manager to say that he was not taking his medications correctly, nor his insulin. The property management indicated that Joe was going to various other tenants in the building wanting them to “help with his needles”. He began to decline physically and made several ER trips, usually related to high blood sugars. His vision began to decline, he had a hard time to walking, and his posture became very stooped over. During one home visit to discuss his medications with him, the case manager discovered that he could not even read the bottles. The case manager immediately called the VNA to request they resume their visits right away, which they did for a while until the same cycle happened again. One time he totally lost his insulin and syringes but said people at the housing complex stole them. The case manager worked with his doctor’s nurse, and several local programs to get him a voucher for more insulin as he did not qualify yet for a medication refill under Medicare D.

The case manager has known Joe now for years. In addition to the prominent physical changes observed, there have been marked cognitive and behavioral changes. He was born one of 10 children who all have varying degrees of learning difficulties and he never learned to read or write well. However, he was always happy, kind and fun loving. Now, he regularly presents as angry, suspicious of others and sometimes hostile. He exhibits a lot of paranoia, believing that many have “done him wrong” and accusing several people of stealing his money, clothing, medications and more. He has become quite unreasonable and obstinate so generally when options to help him are offered he refuses and says that he can manage himself, when the evidence is he cannot. He has very poor hygiene and it appears likely he rarely, if ever, bathes. Upon one home visit, the case manager found that Joe had his tub full of stuff so could not shower if he wanted to. He is unkempt; does not manage his money well as evidence by unpaid bills that pile up. He shows no understanding of how to manage his diabetes. During one doctor’s visit when the case manager accompanied Joe, the nurse found his blood sugar to be very high. When she told him what it was, he said he needed a piece of candy to bring it down. She told him that would raise it more so he said to give him some orange juice then. He often eats at various shops in town, and eats primarily foods which raise blood sugar and very little protein. He refused Meals on Wheels when this was offered to him. He has started going back to the local drop-in center that serves both breakfast and lunch, which has been helpful.

Joe has a lifelong history of hoarding, which recently became out of control in his apartment. The property management threatened eviction because there was no visible means of egress and he even had the kitchen and bathroom piled high with things. He had two beds piled to the ceiling with boxes so he slept in a very small open area on his couch. The property managers had to go in and clean the place once as on inspection they found rotting food and maggots. They called the case manager often with complaints of the condition of the apartment so the case manager sought to hire a woman known to help hoarders clean and organize. However, client refused her help, saying he had friends who could help him. His family also called the case manager with offers to help, but he refused their help as well. They expressed many concerns about his overall decline and wanted to see him living in a supervised setting. I made a referral to the elder care program to ask for their help with the hoarding and behavior challenges as the property management said they would evict him if something was not done soon. On several occasions, the case manager and elder care clinician met with Joe and mapped out a plan with him, however he was unable to follow through with the plans. Finally, the Fire Marshall came in and condemned the unit. The property management began the eviction process and despite the good efforts of Legal Aid Senior Services, the client was finally evicted.

The case manager and drop-in center staff made many contacts trying to find Joe other housing when it became evident he would be evicted. We also involved several local programs to help with funding needed to obtain a new apartment. The collaborating partners all felt Joe would be better served if he moved to a residential care home. He was to move to a local residential care home but then refused. He was also offered mental health housing and refused that. During his homeless phase the case manager worked with the AHS Field Service Director; APS and OPG were also involved with this client along the way. Economic Services granted him GA funding to stay in a hotel until a new apartment was recently found.

Joe is already having problems in his new apartment and both the drop-in center and doctor's office would like to see more in-home supports. The case manager met with Joe in November to complete a Choices for Care application and he refused, saying he can do everything for himself. In response to this the case manager suggested that the team, consisting of the drop-in center staff, elder care clinician, and case manager, meet to discuss next steps for Joe. The case manager has mentioned guardianship to many over the past few months and although most agree he would benefit, no one has wanted to petition for it.

SELF-NEGLECT CASE EXAMPLE B

The client is a 67 year-old woman who has been involved with the local Area Agency on Aging for the past 3 years. Mary originally came to us after she was given an eviction notice from her Section 8 apartment and legal aid became involved. Upon the first meeting it became quite evident that Mary suffered from mental health issues (later to be discovered as paranoid schizophrenia) that were not being treated. She had severe delusions about her landlord and other community members, as well as major issues with hoarding.

The first time the case managers entered her apartment to assess the situation they were unable to climb the stairs and navigate the apartment due to the sheer number of piles of clothes, old papers/boxes, and rotten food. She also showed the case managers the bathroom where she refused to use the toilet and claimed that the phases of the moon effected how her bathroom functioned. The case managers spent several weeks gaining the trust of this client and working with legal aid to postpone the eviction process, as well as working with VT State Housing Authority to coordinate the requirements of a new apartment. During this time the case managers also attempted to work with the local mental health agency to acquire support for this challenging case, but they were unable to help because this client had “burned her bridge” with this agency in the past.

The case managers continued to put in countless hours, along with AmeriCorps volunteers, to attempt to find a landlord who would rent to this client, as she had “burned her bridges” with the local housing coalition a few years prior. Upon finding an apartment, many more hours were used in trying to coordinate the packing/moving of this client to an apartment that was only a few blocks away. The case managers tried to coordinate the packing with the AmeriCorps volunteers as well as local church volunteers. This situation exploded when the client accused the volunteers of putting her valuable items in the trash, which is a major issue that faced with hoarding clients. The client became furious and threatening to the volunteers. At this time, the case managers and representative from the housing authority worked hand in hand with the client and her out of town daughter to coordinate the final phase of the move. Her daughter flew in for a week to try to reason with her mom, who eventually accepted the move over being homeless. At this time the daughter also tried to get her mom to stop taking her “herbs” and to seek medication to manage her mental health issues, which failed because the mental health agency would not speak with the daughter. The client did agree to allow church volunteers to continue to assist in the move and unpacking of her items but as expected, 3 years later her boxes have not been fully unpacked and the conditions of the apartment are similar to the previous apartment.

The case managers continue to work on helping this client maintain her public benefits and housing voucher, but are still unsuccessful in getting mental health assistance for this client because she is technically competent and is choosing to not accept services. It is just a matter of time before this landlord is unable to deal with the hoarding behavior or threats that come from her delusions become too much and he chooses to start the eviction process. As is the case in other similar self-neglect situations, it would be most helpful to have easy access to mental health services, funds to help overcome barriers, a pool of trained volunteers to assist with tasks, housing specialists, as well as more staff hours to dedicate to these time consuming situations.

SELF-NEGLECT CASE EXAMPLE C

The local Area Agency on Aging (AAA) received a referral for Ruth in May of 2012. Ruth is a 63-year old woman who was living alone with her dog in a mobile home in a rural setting. The mobile home is on land owned by her brother from whom she has been estranged. Ruth had been referred to the AAA shortly after she had been fired from her job for reasons unknown. The initial reason for the referral was to assist her with applying for unemployment benefits. Upon visiting with Ruth, it became clear that she was unable to follow through with most tasks given to her to assist in this process. Her case manager attempted to assist her with public benefit applications, Home Share applications, and unemployment, but because Ruth was unable to follow through and provide the necessary information and documentation the applications could not be completed. Soon after meeting and starting to work with Ruth, she shared with her case manager that she was an insulin dependent diabetic, on dialysis (and had been for a number of years) and had a host of other medical issues. It gradually became clear to the case manager that, what at first seemed to be passivity about her lack of follow through, was clearly impaired cognition and it was apparent that Ruth was unable to effectively manage her diabetes and lacked the understanding about the importance of her dialysis treatments.

About 6 months after Ruth began working with her case manager, she started refusing to participate in dialysis for unknown reasons, to the point where she became toxic and required hospitalization. She was released home with a plan to make sure that she was able to make her regular dialysis appointments. This worked for a while until about 6 months later when she again began refusing to participate in dialysis. She gave her case manager her a variety of reasons for her refusals – i.e. it was too cold out, she didn't feel well, she wanted to stay home, it was a nice day , etc. During this period the case manager attempted to assess Ruth's ability to comprehend the danger of not accepting dialysis, offer alternative options for getting to dialysis and initiating conversations between her physician's office, dialysis social worker and Ruth to help her understand the concerns and determine if she was actively choosing certain death if she didn't agree to dialysis.

After 10 days without dialysis and 6 trips to the ER within a 2-day period, she was again admitted to the hospital. The hospital completed an emergency guardianship petition and Ruth was assigned a temporary public guardian. During this entire process, Ruth was committed to returning to her home, to live and be supported by her niece, who offered to be a live-in caregiver. Her guardian applied for Choices For Care on her behalf and she was found eligible. Her team of providers all felt that placement in a facility (residential or nursing home care) was the best option for her. Unfortunately, there were no facilities in the state of Vermont willing to accept her due to her dialysis need and attempts to elope. After 4 months

in the hospital, she was discharged home with CFC services and supports from the Money Follows the Person program. The AAA, VNA, Office of Public Guardian, the hospital dialysis/social work programs, and a local transportation provider all worked in collaboration to provide support to this woman to achieve her goal of receiving services at home. The court eventually granted full and permanent guardianship.

Within a few days of returning home, she was refusing to allow caregivers into her home, not answering her door or phone, not taking her medication as directed, not providing care to her dog (allowing the dog outside trips), among other concerns. She quickly began refusing to regularly participate in scheduled dialysis. Her niece, who had been identified as a live-in caregiver, stayed sporadically and opted to provide little to no assistance with care. After one month of failing health and acceptance of services, she again was admitted to the hospital, where she remains now, continuing to seek placement.

SELF-NEGLECT CASE EXAMPLE D

A referral came from community partners who had exhausted their resources working with an elder who had come to them requesting repairs on their home. The community partners had chosen to focus on one area of repair that the elder had requested but realized there were other serious safety and health hazards for the elder who refused to leave the home now for safer options.

As the case manager built up a relationship with the elder, it became apparent that the community partners with all good intentions had inadvertently given the false hope that the home was going to be made sound and livable and that somehow funding would be available to support the elder living there. The elder self-identified to the case manager that the home was structurally unsound, with no working utilities or working appliances. When the case manager explored the issues along with the elder's budget, there was not enough income to pay monthly bills coming in that would be needed to live there, and no resources to pay for repairs to make the home safe. In the relationship building and work on issues in this case, as well as many others, it is most often multiple community partners that are or have been involved. Support systems were weak with the elder having burned bridges with both community and family.

To complicate matters, in the often rugged terrain of the area, to connect with an elder can be an hour one way from the office just to get to their home. Many do not have working phones or neighbors to relay messages though. Landlines are often too big an expense for the elder to maintain. There are many places in the area where a case manager with a cell phone does not get service so it means driving a distance from the elder's home to even reach the office or other providers. Even the simple issues embedded in larger complex cases such as these end up taking immense amount of time.

One of the things that could have helped this situation would have been if the community partners and the case managers had developed a relationship with each other prior specifically on how they were to work together in these situations, to clearly know the roles and boundaries of each program, and to have training together on the issue of self-neglect and hoarding. Having this type of training would have put all partners on the same page, knowing there are some commonalities that might be expected, such as the length of time it takes to build relationships with the elder and strategizing how to work within the elder's financial means for long term sustainability. The other key factor is giving the case manager the time to work on these cases, acknowledging that the workload for the situations require expertise, time and good self-care on the part of the case manager.

SELF-NEGLECT CASE EXAMPLE E

Clara is a 76-year old female who has been receiving services provided under the Older Americans Act since 2007. At that time she was referred by her doctor's office due to poor nutrition, which was assessed to be the result of self-negligence. Her husband had passed away two years before, and she lived alone in a cluttered subsidized apartment. She was homebound and isolated. She has diabetes, angina, memory loss, incontinence, and depression, and fatigues easily. She needed help with transportation, insurance, cleaning, and meal preparation. She began to receive counseling through the elder care clinician program at that time. She also has received intermittent home care from the local Visiting Nurse Association. Little helped to 'fix' the cluttered apartment but headway in terms of nutrition thru meals were successful. She was placed on the moderate needs wait list for homemaker services but at the time was not on Medicaid.

In Fall 2008 she went onto the moderate needs program when her name came up off the wait list. She started to receive homemaker services at that time. There was a noted improvement in her housing and thus desire to have friends and visitors over. She had a senior companion whom she developed a close relationship with. Family did not feel she should be living alone. During the course of the work there were numerous family problems including her financing her children's manipulations of her money. APS became involved but she did not want their involvement. Several years later and as things continued to deteriorate with her finances, her daughter was found to be exploiting her and charges were put forth. A representative payee was put in place to aid with financial resources and to eliminate the exploitation. She was steadfast in her desire to remain in the community. Her ability to put limits and boundaries in place with her family grew with support from the AAA Case Manager, Home Health staff, ElderCare Clinician and rep payee. She began to get out to the senior center and continued living independently in her apartment. Her memory impairment deteriorated and she eventually moved in with her son where she was cared for by family. She lived with him for about a year and came off the moderate needs program during that time. The son and daughter-in-law began to experience more behavioral. Clara has a diagnosis of dementia but is very adept, thus leading to decreased visibility and limited acknowledgment of her illness. She was alone during the day as her son and daughter-in-law needed to work, so she went on the moderate needs program for Adult Day services. Her son began to seek placement as he was feeling burned out and her behaviors were increasingly challenging to him. Just as she was to be placed a friend came into the picture and offered to have her live with her. This process revealed more of her impairment and challenges to caring for herself. The case manager worked on applying for Choices for Care this past spring and she is now cared for at the home of her friend and Adult Day on the Choices for Care Program.