Report to

The Vermont Legislature

Recommendations Relating to Self-Neglect in Vermont

In Accordance with Act 156 of 2020, Sec. 7

Submitted to: House Committee on Human Services

Senate Committee on Health and Welfare

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Executive Summary

In October 2020, Vermont enacted The Older Vermonters Act to further the State's development of a "comprehensive and coordinated system of supports and services for Older Vermonters".[1] The Older Vermonters Act established a "Self-Neglect Working Group to provide recommendations regarding adults who, due to physical or mental impairment or diminished capacity, are unable to perform essential self-care tasks".[2] This report is submitted under the requirement of Act No. 156, Section 7(e).

From April 2021 through April 2022, the Working Group met monthly. The Working Group established three subcommittees which met separately. The Working Group also developed and administered a survey to stakeholders statewide regarding self-neglect. The combined efforts of the Working Group's membership led to the development of six distinct recommendations:

(1) Training: Develop and implement a standardized training for Vermont providers to ensure that self-neglect is identified and appropriately responded to.
(2) Intake and Referral: Develop and implement a clearly defined intake and referral process for adults 18+ who may be self-neglecting.
(3) Screening Tool: Create a self-neglect screening tool to be adopted by organizations to assist in the identification of self-neglecting individuals.
(4) Coordination: Expand the functionality of existing service providers to include coordinating responses to instances of self-neglect, and establish new multidisciplinary teams where regionally absent to perform similar functions.
(5) Oversight: Designate an entity to conduct the following three objectives: (a) oversee provider response systems for individuals exhibiting signs of self-neglect, (b) provide grant funding to those providers, and (c) collect self-neglect data in Vermont.
(6) Resources: Identify an organization or organizations to receive, and respond to, self-neglect referrals concerning individuals ages 18+; provide additional funding to such organization or organizations proportionally based on caseloads.

In addition to the six recommendations developed above (which are specific to determinations made as required by Sec. 7(c), of Act 156), the Working Group offers two additional considerations (A & B) that may inform all six recommendations:

(A) Incorporate past recommendations submitted to the Vermont Legislature regarding self-neglect from: (a) a 2012 Legislative report, and (b) a 2014 study. In 2012, a different self-neglect working group established by the Vermont Legislature submitted a report to the legislature containing recommendations regarding self-neglect similar to some of those presented here. Following that report, a 2014 study commissioned by DAIL offered further recommendations.

(B) Provide the funding necessary to appropriately address self-neglect. Currently, the State provides limited funding to the Area Agencies on Aging (AAAs) to provide services to self-neglecting individuals age 60 and older.

[1] Act No. 156, Section 1
[2] Act No. 156, Section 7(a)

Further, the State does not currently fund any entity to provide direct services to self-neglecting individuals under the age of 60. The Working Group has determined that this limited funding is insufficient to support the AAAs actual costs in responding to self-neglect. Thus, the Working Group recommends that the State dedicate a level of funding to agencies/organizations responding to self-neglect that is proportional to the need (i.e., based on provider caseloads, and for clients age 18+). The Working Group recommends that the State allocate such funding via RFPs to facilitate competition among potential service-providers. Of note, expanding eligibility criteria and/or funding for existing care programs is insufficient to address self-neglect due to the unique, field-based services required for which current providers are not equipped.

Introduction: What is self-neglect?

Nationally, "self-neglect" is a general term used to describe a vulnerable adult living in a way that puts their health, safety, or well-being at risk. Prioritizing self-determination, Vermont's definition of self-neglect further specifies that the behaviors in question must be the result of diminished capacity related to a medical or behavioral health issue. Specifically, Vermont defines "self-neglect" to mean:

> An adult's inability, due to physical or mental impairment or diminished capacity, to perform essential self-care tasks including (i) obtaining essential food, clothing, shelter, and medical care; (ii) obtaining goods and services necessary to maintain physical health, mental health, or general safety; or (iii) managing one's own financial affairs. The term "self-neglect" excludes individuals who make a conscious and voluntary choice not to provide for certain basic needs as a matter of lifestyle, personal preference, or religious belief and who understand the consequences of their decision. 33 V.S.A. § 6203(11).

Many people think they have an intuitive understanding of self-neglect, but often fail to consider all the implications a self-neglecting individual may have on their family and community. On a related note, many do not understand how some basic services can help save the life of a self-neglecting individual in some instances and, conversely, how complicated a self-neglect case may become, posing challenges in protecting the health and safety of not just the self-neglecting individual, but also their family and neighbors.

To help provide context towards understanding the findings and subsequent recommendations of this report, the Working Group offers two brief case examples that happened recently in Vermont. The first, a simpler case addressed with existing services in Vermont. The second, a more complex case without adequate Vermont services.

Case Study 1

An 80-year-old man, "Jack"[3], was referred to the local Area Agency on Aging (AAA) by his neighbor, who noted that Jack appeared unkempt, had a strong body odor, and had recently been seen walking in the snow without shoes on. Upon receiving the referral, a case manager from the AAA reached out to Jack to schedule an initial visit. At the visit, Jack was friendly and described how he prepares meals, grocery shops, takes medications, and bathes and changes clothes regularly. However, the case manager observed that the home was cluttered and that Jack was in soiled clothes and appeared not to have bathed in several weeks. Jack also presented with memory impairment. He could not correctly identify the season despite there being snow on the ground. At the visit, Jack provided contact information for a daughter who lived in Florida.

Based on the initial assessment, the case manager determined that Jack met Vermont's definition of self-neglect. With Jack's permission, the case manager followed up with the Jack' daughter, who reported that she was unaware of her father's condition. She noted that he had appeared clean, well-fed, and was not confused during her visit

[3] Name changed

approximately 2 months prior. With the knowledge that Jack's self-neglecting behaviors were new, the case manager recommended to Jack that he follow up with his primary care physician for an evaluation. Jack's physician diagnosed JS with, and treated Jack for, a urinary tract infection. That infection had impaired Jack's cognitive ability. At a follow-up visit two weeks later, Jack presented with minimal confusion and the capacity to care for himself. At that point, the case manager determined that Jack no longer met the definition of self-neglect and ceased the provision of case management services.

Case Study 2

Adult Protective Services (APS) received a report from Law Enforcement (LE) and EMS regarding a 78-year-old female, "Mary"[4], with undiagnosed progressive dementia. Mary was the caretaker and guardian for her three adult children, all of whom had cognitive impairments and significant physical disabilities that required skilled nursing level of care. LE and EMS had expressed concerns regarding Mary's lack of selfcare, the related lack of custodial care being provided to the adult children, and the condition of Mary's home.

Concerns had been building over a period of months with law enforcement having conducted 12 visits to MM's home in 2021. Prior self-neglect reports to APS resulted in referrals to the AAA, as well as law enforcement referrals to the Agency of Human Services Field Director who, in turn, reached out to Vermont Chronic Care Initiative (VCCI).

Recognizing a potential case of statutory neglect by a caregiver (Mary), APS assigned a Service Navigator to assess the situation in-person. Within a couple of days, APS and VCCI went with LE for a joint home visit. Mary's home was cluttered with unsanitary living conditions. It was determined that no one in the home could pay bills. In fact, multiple bills were past due, including for electricity, which was scheduled for shut off. Mary refused assistance, stating that the family was fine. The team ensured that the family had food and medication while long-term solutions were sought.

The situation continued to deteriorate over the next few weeks with no service provider having authority or means to intervene on behalf of Mary or her three adult children. When the utilities were scheduled to be disconnected mid-winter, LE decided to take the family into protective custody and transport them to the local emergency department, despite there being no medical evaluation determining an emergency. This was at the height of the pandemic. The family's arrival at the ED exhausted the hospital's capacity, causing the diversion of all other ambulances to other facilities. The DAIL Commissioner called an emergency meeting, requested APS to file a petition for emergency guardianship appointment for all four family members, authorized funds to support the family's placement in a skilled nursing facility, and delegated staff to find facility availability for placement pending the petition's filing.

APS filed the emergency petition. The next business day, the Court appointed the Office of Public Guardian (OPG) as temporary guardian of the family, and the family was

[4] Name changed

moved to a skilled nursing facility. OPG worked with the skilled facility to meet the needs of the family.

Vermont's current laws and systems provide governmental and nongovernmental agencies limited ability to override an individual's personal choices, even where those choices may cause the individual harm. However, where individuals *are* self-neglecting, care coordination, medical intervention, and social supports can result in positive outcomes and reduced risk of harm.

Self-Neglect is not in itself a diagnosis, but rather a state of being and collection of behaviors that can be caused by any number and combination of social and medical risk factors. An individual could be considered self-neglecting for a short period of time or decades. Because each individual case of self-neglect is unique, successful interventions must be tailored to the individual, taking into account their personal preferences, histories, medical diagnoses, resources, and social networks. Whether an intervention is successful, and how quickly progress can be made, often depends on the individual's willingness to engage with a professional(s).

Self-Neglect Issues per the Older Vermonters Act

How to identify adults residing in Vermont who, because of physical or mental impairment or diminished capacity, are unable to perform essential self-care tasks and are self-neglecting.

Vermont's Current System for Identifying Individuals Who Engage in Self-Neglect

Vermont does not have a singular or centralized system for identifying individuals engaged in self-neglecting behaviors. Day to day, cases of self-neglect are identified by a wide range of individuals, governmental agencies, and nongovernmental organizations, including family members, friends, and neighbors of potentially self-neglecting individuals; law enforcement and first responders; case managers; field workers for the Agency of Human Services; and hospital social workers.[5]

Those who spot potential instances of self-neglect are meant to refer, or report, cases to the Area Agencies on Aging (for persons over 60 years old) or AHS Field Service Directors (for persons under 60 years old). However, there is a persistent issue throughout Vermont with lack of adherence to this referral process, in part due to lack of awareness of the appropriate referral pathways. In most instances, cases of self-neglect are incorrectly referred to APS, which has no statutory authority to investigate or provide services to allegedly self-neglecting individuals. When APS receives reports of self-neglecting individuals who are age 60 and over, referrals are made to the AAAs; when

[5] This Working Group underscores that community members play a critical role in identifying self-neglecting individuals given their geographic proximity to these individuals and related ability to observe precursor or concurrent conditions to self-neglect, like social isolation, dementia, mental illness, sudden changes in hygiene/cleanliness of home or person, and financial insecurity.

APS receives reports of self-neglecting individuals under the age of 60, it refers those cases to Vermont's AHS Field Service Directors.

The Area Agencies on Aging (AAAs) have the purpose, expertise, and limited state funding to formally assess individuals for self-neglect and coordinate responsive services for those over age 60. Once the AAAs receive a referral that an individual (age 60 or over) may be self-neglecting, they take several steps including using a comprehensive assessment tool to identify whether, and to what extent, self-neglect is occurring. In order for AAAs to meaningfully identify whether and how an individual is self-neglecting, determine what responsive services are potentially relevant, and facilitate the provision of services, the AAAs typically must invest considerable time, resources and effort with a client who is exhibiting self-neglecting behaviors before earning the client's trust. The Working Group observes that, in the context of self-neglect, mistrust of services is a common barrier to acceptance of services.

By contrast, for individuals aged 18-59, there is no organization or agency in Vermont that focuses on identifying and/or coordinating services for self-neglect. Unfortunately, individuals under the age of 60 do engage in self-neglect (as observed and reported by Vermont's Designated and Specialized Service Agencies, field service workers, emergency rooms, and primary care providers, among others). While such cases may be reported to the AHS Field Services Directors, there is no specific agency designated and resourced to provide direct supports and service coordination to these self-neglecting individuals.

Evidence-Informed and National Best-Practices for Identification of Self-Neglect

While considering evidence-informed best practices and national studies surrounding self-neglect, it is important to be mindful of the high value that Vermont places on individuals' rights to self-determination. With that fact in mind, studies that are specific to self-neglect in Vermont should be given special consideration. The Working Group reviewed the recommendations put forth by Kelly Melekis in the report "Self-Neglect: A Statewide Assessment in Vermont" (Day et al, 2014). The Melekis Report made several recommendations for improving how Vermont identifies and responds to self-neglecting behaviors. The Working Group supports many of the study's recommendations, such as knowing and understanding the client; acquiring relationship-building skills; implementing a multidisciplinary team approach; and engaging additional support and training. Specific strategies identified in the Melekis Report include:

1. Clarification of the reporting and referral process (and the establishment of these processes via formal policy);
2. Specialized training and/or access to expertise via consultation when responding to cases of self-neglect;
3. Care coordination services as a component of the response to cases of suspected self-neglect;
4. Community engagement, to possibly include:
    a. Informing the public regarding the nature of self-neglect and process for report, referrals, and response.

   b. A public awareness campaign about self-neglect to the concerned community members and families.
   c. Additional support for families and caregivers.
   d. Organized Volunteer/peer/companion network.
5. Further research to better understand the relationship between self-neglect, mental health/cognitive impairment, and the intersection of other risk factors. *Id.*, pages 30-32.

Communities can help by strengthening the networks of organizations and service providers who understand the complexity of self-neglect and who work collaboratively to support individuals to access services and supports. In addition to the AAAs, this includes Designated and Specialized Services Agencies, home health agencies, public safety, law enforcement agencies, and more. A robust network of agencies working closely together is more likely to be able to respond quickly and effectively and to provide services and supports that mitigate the risks associated with self-neglect.

Recommendations

Training: Develop and implement a standardized training for Vermont providers to ensure that self-neglect is identified and appropriately responded to. Training should be designed to educate about the risk factors, known causes, and behaviors associated with self-neglect, and where to refer concerns regarding self-neglect.

Oversight: Designate an entity to perform the following three functions: (a) oversee provider response systems for individuals exhibiting signs of self-neglect, (b) provide grant funding to those providers, and (c) collect self-neglect data in Vermont. This entity will oversee, administer, and assess outcomes of statewide educational campaign designed to increase awareness in communities and among stakeholders about self-neglect.

Screening Tool: Create a self-neglect screening tool to be adopted by organizations to assist in the identification of self-neglecting individuals. This self-neglect screening tool will be made available to entities that may interact with individuals in Vermont exhibiting self-neglecting behaviors. Best practices would seemingly need to encourage and include such considerations in the training and implementation of self-determination/capacity assessments as well as assessing the prevalence of self-neglect.

How prevalent self-neglect is among adults in Vermont, and any common characteristics that can be identified about the demographics of self-neglecting Vermonters.

Prevalence of Self-Neglect:

Determining the prevalence of self-neglect among adults in Vermont, along with identifying the characteristics of people most likely to engage in self-neglect, are critical tasks. Both determinations are necessary for the implementation of a system that: (1) prevents self-neglect; (2) intervenes effectively when self-neglect is identified; and (3) supports the needs of a person identified as self-neglecting. As discussed below, barriers are in place now that prevent an accurate assessment of the prevalence of self-neglect among Vermonters and make it difficult to present a clear picture of the people most likely to engage in self-neglect.

In Vermont, APS tracks the number of referrals it receives for people who may be engaging in self-neglect behaviors. These referrals occur *despite* APS having no statutory authority to respond to self-neglect, and conditioning providers to that fact when they make a report and are informed self-neglect cannot be investigated by APS. Yet, as demonstrated in Table 1 below, APS receives a substantial number of referrals related to self-neglect each year. Note that the percentage of total referrals related to self-neglect has risen steadily over the last five years. Demographic data is not collected and there is no data available to inform on the characteristics associated with self-neglect referrals to APS.

Table 1. Vermont Adult Protective Services Referrals for Self-Neglect, 2017-2021. The numbers of referrals cited below have increased nearly 50% in the last five years. While there may be a small number of duplicated individuals if the same case is referred more than once, we can assume this is an under-reported population for a number of reasons; foremost, self-neglecting individuals often experience social isolation that limits exposure and opportunities for reporting by others.

Year	Number of Referrals	Percent of all referrals received
2017	273	7.56%
2018	343	8.48%
2019	272	9.69%
2020	417	12.03%
2021	408	11.71%

The Area Agencies on Aging, designated as the entity to receive self-neglect referrals for individuals over 60 in Vermont, collects data related to the prevalence of self-neglect. Because services are predominately provided to individuals over 60, the data below reflects only a portion of the potential self-neglecting population in Vermont. Data from the five Area Agencies on Aging can be seen in Table 2 below.

*Note: We do not have population level prevalence data in Vermont.

Table 2. Area Agency on Aging data on self-neglect, 2017-2021.	**Number of Referrals**	**Number of Self-Neglecting Clients Served**	**Hours Spent Providing Self-Neglect Services**
2017	Incomplete data	Incomplete data	Incomplete data
2018	Incomplete data	Incomplete data	1,975.75 hours
2019	104	84	2,163.5 hours
2020	150	112	2,344 hours
2021	178	206	2,787.5 hours

Recommendations

Intake and Referral: Develop and implement, a clearly defined intake and referral process for adults 18+ who may be self-neglecting. This system will adopt a statewide standard process for the reporting of referrals, assessments, and outcomes as related to self-neglect. To help establish this reporting system, the Working Group also recommends conducting a feasibility review to determine whether a shared data system could reasonably be established to streamline data sharing and use across providers and stakeholders in Vermont.

Oversight: Designate an entity to conduct the following three objectives: (a) oversee provider response systems for individuals exhibiting signs of self-neglect, (b) provide grant funding to those providers, and (c) collect self-neglect data in Vermont.

What resources and services currently exist to assist Vermonters who are self-neglecting, and where there are opportunities to improve delivery of these services and increase coordination among existing service providers; and What additional resources and services are needed to better assist Vermonters who are self-neglecting.

Current State of Services & Resources

Currently, individuals exhibiting self-neglecting behaviors are referred to the Area Agencies on Aging (for those 60 and older) and Agency of Human Services Field Services Directors (for those under 60). The AAAs are equipped to provide individualized case management, whereas the AHS Field Services Directors utilize a cross organizational collaboration model to recruit resources that may be of benefit to the individual, but do not utilize a self-neglect assessment tool, make self-neglect determinations, or work directly with individuals who present with self-neglecting behaviors. Like the Area Agencies on Aging, the AHS Field Directors currently struggle to adequately meet the needs of self-neglecting Vermonters with currently available resources and staffing capacity.

For individuals over 60, AAA Case Managers work on engaging and developing a rapport with self-neglecting individuals. If they are successful at building a relationship, they can access resources to support the person that include, but are not limited to, referrals to Designated and Specialized Service Agencies, homeless shelter staff, Community Action Agencies, churches, hospitals, domestic violence organizations, local state agencies, and local businesses. For individuals under 60, the AHS Field Services Directors have strong community relationships and have demonstrated success in convening multi-disciplinary provider teams to provide resources and coordination that would not be available without this level of intervention. While they do not have the funding and capacity to work directly with self-neglecting individuals, they serve as a coordinating entity which ensures additional partners are involved in these cases that can provide multiple supports. These most often include mental health services, addiction treatment and recovery resources, housing, caregiving, medical care, guardianship petitions, access to food, assistance with bills, home maintenance, and ongoing case management.

There is confusion both with local providers and the general public in knowing where to refer matters of self-neglect. Given as much, there appears to be substantial risk that self-neglecting individuals could "fall through the cracks" of the current system; that is, their needs may remain unnoticed and/or unmet.

Evidence-based practices:

There is little research on evidence-based practices to address self-neglect. One summary article stated: "Despite the paucity of empirical evidence of specific strategies, a multidisciplinary team approach with a robust system of collaboration, communication, and risk sharing is believed to be effective for self-neglect issues. Each part of the multidisciplinary team may focus on a specific area, that is, improving daily function, to ensure the safety of the elder, promote knowledge and understanding within a community, and keep efficient and transparent lines of communication. Medical teams, mental health professionals, community educational programs, social workers, and agencies of financial service must also be included to address the depth of self-neglect issues" (Dong, 2017).

Two states currently researching self-neglect (Texas and Oklahoma) have reported that: (1) streamlining the referral process and (2) training are the most beneficial components of successful interventions for self-neglect.

Recommendations

The Working Group makes the following recommendations to enhance the statewide system of services and supports relating to self-neglect.

Intake and Referral: Develop and implement a clearly defined intake and referral process for adults 18+ who may be self-neglecting.

Screening Tool: Create a self-neglect screening tool to be adopted by organizations to assist in the identification of self-neglecting individuals.

Resources: Identify (through RFP) an organization or organizations to receive, and respond to, self-neglect referrals concerning individuals ages 18+; provide additional

funding to such organization or organizations proportionally based on caseloads. Currently, the AAAs receive and respond to referrals regarding self-neglect in individuals age 60+ and receive static, limited funding to do so. Whether the AAAs or a different entity ultimately perform this function, that entity needs funding substantially beyond what AAAs currently receive in proportion to the given caseload.

In other states, like TX, agencies responding to self-neglect have discretionary funds to use to resolve urgent client needs—from the paying of an electricity bill to the clean-up/sanitization of a home. We recommend that agencies/organizations designated to respond to self-neglect be provided with discretionary funds to address urgent client needs, as well. Sometimes the application of discretionary funds can prevent a potentially-resource-intensive circumstance from ballooning.

Oversight: Designate an entity to conduct the following three objectives: (a) oversee provider response systems for individuals exhibiting signs of self-neglect, (b) provide grant funding to those providers, and (c) collect self-neglect data in Vermont.

Coordination: Expand the functionality of existing service providers to include coordinating responses to instances of self-neglect, and establish new multidisciplinary teams where regionally absent to perform similar functions.

Currently, regional multidisciplinary teams exist in various formats to assist in coordinating wrap around services to locals in need. We recommend that existing teams expand their functionality to include coordinating responses to instances of self-neglect, and that new multidisciplinary teams be developed where regionally absent to perform similar functions. Several other services/programs are integral to the support of self-neglecting individuals and should be considered part of the multidisciplinary solution. They include but are not limited to the Eldercare Clinician Program, Hoarding Taskforces, and Permanent Supportive Housing.

Training / Education: Develop and implement a standardized training for Vermont providers to ensure that self-neglect is identified and appropriately responded to.

- Education of the public and of professionals is needed. A public education campaign should address:
    - What is self-neglect?
    - Where can the public refer matters of self-neglect?
    - What services and supports are available to self-neglecting individuals?
- An education campaign directed to professionals should address:
    - What is self-neglect?
    - Where can matters of self-neglect be referred?
    - What roles do other agencies/organizations play in responding to instances of self-neglect?
    - What sources of funding exist to address self-neglect?
    - Best practices in identifying and responding to self-neglect.
    - The term self-neglect is stigmatized and needs to be understood
    - Note: This professional education should be provided to the following agencies/organizations, among others: Town Health Officers, Town

Nurses, EMS squads, law enforcement, primary healthcare providers, hospitals, and community service groups.

How to prevent self-neglect and identify adults at risk for self-neglect

Prevention Efforts Regarding Self-Neglect in Vermont

The October 2021 survey of self-neglect stakeholders revealed that a common prevention method employed by agencies that work with Vermonters who exhibit self-neglecting behaviors was through repeated attempts to engage, or check-ins by professionals. The primary services those agencies are providing to support them are case management, service coordination, and education. Some of the most effective programs identified in the stakeholder survey were trainings offered to older Vermonters to empower them to remain healthy and avoid self-neglecting behaviors. The survey responses specifically mentioned programs addressing healthy nutrition, self-care, depression, dementia, and hoarding. There were also stakeholder examples citing the importance of prevention focused, person-centered training for providers and caregivers.

The most consistently mentioned barrier to efforts to reduce self-neglect was lack of established authority for most State or partnering entities to do essential tasks in addressing self-neglect, such as entering a home for a welfare check, determining capacity, and moving someone if determined necessary.

Another barrier in supporting older Vermonters who are self-neglecting is insufficient support and recognition for caregivers. Caregivers, whether paid or unpaid, are the most consistent point of contact for many older Vermonters. Increasing respect, support, and compensation for caregivers would ensure they continue to provide their time and invaluable services on a regular basis.

Finally, we must address the lack of resources we are allocating to programs that are not built to support Vermonters who exhibit self-neglecting behaviors. These individuals are struggling with lack of technology, transportation, and even funds to do minor home repairs. In addition, challenges with mobility, hearing and sight make it increasingly difficult for them to participate in educational and community programs. In addition to these barriers, what makes serving these individuals particularly challenging is self-neglecting individuals typically will not engage in provider services on their own. Existing Vermont providers rely on self-referrals and are not equipped to provide the field-based, pro-active relationship building that is often necessary to establish trust and encourage engagement. For this reason, expanding eligibility criteria or funding for existing Vermont providers would still be an inadequate approach to addressing self-neglect. New service models must be deployed.

Identifying Adults at Risk for Self-Neglect

In Vermont, there is a lack of consistent or expected practices to identify adults at risk of self-neglect. Survey responses reflect that efforts to identify at-risk individuals (which may also be characterized as prevention measures) include deliberate check-ins with at-risk consumers, training, and education. Training and education about self-neglect addresses consumers, community members, and providers.

Despite the fact that there are, as yet, no best practices, what is clear from the research is that relationship-building and time are crucial elements in providing services to people who exhibit self-neglecting behavior. For instance:

- Building a therapeutic relationship with self-neglecting clients and sensitive comprehensive assessments are key to evaluating the situation. (Braye et al, 2011; Day and Leahy-Warren, 2007; Dong & Gorbien, 2005)
- Seeking to understand self-neglect from clients' perspectives is very important (Band-Winterstein et al, 2012, Day et al, 2013)
- In many case studies, it may take two years from the initial referral until a self-neglecting individual finally consents to help. Throughout this period, providers, such as public health nurses, continue to reach out and offer services. (Day et al., 2015)
- The evaluation of the elder abuse intervention program ECARE(Eliciting Change in At-Risk Elders), proved that developing relationships with at-risk elders and/or their families prior to suggesting community-based interventions produces statistically significant improvements in the elder's status. Some participants required as long as three months to build a working alliance with outreach specialists before moving on to interventions. Once that alliance was formed, information about available community-based resources was provided that would enhance the elder's safety and promote autonomy in whatever regard best suited the elder's situation. (Mariam et al., 2014).

Recommendations

Training: Develop and implement a standardized training for Vermont providers to ensure that self-neglect is identified and appropriately responded to. Recommendations outlined here mirror those from the 2012 and the 2014 statewide reports on self-neglect in Vermont. Training should be developed for Vermont providers and direct-support professionals and made readily available across the state. Training can help support the implementation of a coordinated response to self-neglect cases through interdisciplinary teams.

Resource: Identify (through RFP) an organization or organizations to receive, and respond to, self-neglect referrals concerning individuals ages 18+; provide additional funding to the organization or organizations proportionally based on caseloads. Service providers should receive the financial support required to incorporate the lengthy process of relationship building with service resistant clients.

Whether the definition of “self-neglect” in 33 V.S.A. § 6203 is consistent with the principles of self-determination in 33 V.S.A. § 6202 and with other principles of self-determination set forth in Vermont’s statutes and rules.

Self-Neglect and Self-Determination

The definition of self-neglect in 33 V.S.A. § 6203 is generally consistent with the principles of self-determination set forth in 33 V.S.A. § 6202, as well as with other principles of self-determination set forth in Vermont’s statutes and rules. This conclusion is based on the Working Group’s review of (1) the definition of self-neglect in Vermont statutes and (2) Vermont statutes that reference self-determination, including those relating to adult guardianship, crime victims' rights, relief from abuse hearings, involuntary commitment and/or treatment, power of attorney, advance directives (and health care surrogates), competency evaluations, protective custody, and health benefits and services. The Working Group recognizes the most successful approaches to self-neglect services involve building trust with a client over time so that they may independently engage in services. Self-determination should not be compromised if adequate services exist to properly address self-neglect. Current Vermont case services are not adequate for relationship-building prior to self-engagement by consumers; the specific needs of self-neglect case services are a key component of the resource recommendations in this report.

Conclusion

Identification of self-neglecting individuals in Vermont is inconsistent, in part due to a lack of public awareness about risk factors and appropriate referral pathways. As a result, self-neglect is likely significantly under-reported in Vermont. Day to day, cases of self-neglect are identified by a wide range of individuals, governmental agencies, and nongovernmental organizations, including family members, friends, and neighbors of potentially self-neglecting individuals; law enforcement and first responders; case managers; field workers for the Agency of Human Services; and hospital social workers.

Determining the prevalence of self-neglect among adults in Vermont and identifying the characteristics of people most likely to engage in self-neglect are critical tasks for fostering a system that prevents self-neglect, intervenes effectively when self-neglect is identified, and supports the needs of those identified engaging in self-neglecting behaviors. Despite the importance of these tasks, there are barriers in place that prevent a clear picture of the prevalence of self-neglect among older Vermonters from being known at this time.

Currently, individuals who are self-neglecting are referred to: (1) the Area Agencies on Aging (for those 60 and older), and (2) Agency of Human Services Field Director (for those under 60). While this system has existed for some time; there is confusion both with local providers and the general public in knowing how to make a referral.

Self-neglect is complex, requiring multiple supports in order to effect change. The primary way organizations are currently supporting those who have been identified as self-neglecting is through checking-ins. The primary services provided to individuals identified as self-neglecting are case management, service coordination, and education.

Effective prevention programs are person-centered and empower individuals.

The definition of self-neglect provided to the Working Group is generally consistent with the principles of self-determination set forth in Vermont's statutes and rules. Furthermore, the Working Group acknowledges the concern that people with capacity, who make a conscious and voluntary choice not to provide for some certain basic needs, may not receive needed services and support – this would be the result for some individuals because of the: (1) current definition of "self-neglect"; and (2) premium placed on self-determination both in Vermont and in federal protections.

In completing its work, the Working Group developed six distinct recommendations relating to self-neglect:

(1.) *Training:* Develop and implement a standardized training for Vermont providers to ensure that self-neglect is identified and appropriately responded to.
(2.) *Intake and Referral*: Develop and implement, a clearly defined intake and referral process for adults 18+ who may be self-neglecting.
(3.) *Screening Tool*: Create a self-neglect screening tool to be adopted by organizations to assist in the identification of self-neglecting individuals.
(4.) *Coordination*: Expand the functionality of existing service providers to include coordinating responses to instances of self-neglect, and establish new multidisciplinary teams where regionally absent to perform similar functions.

(5.) *Oversight*: Designate an entity to conduct the following three objectives: (a) oversee provider response systems for individuals exhibiting signs of self-neglect, (b) provide grant funding to those providers, and (c) collect self-neglect data in Vermont.

(6.) *Resources*: Identify (through RFP) an organization or organizations to receive, and respond to, self-neglect referrals concerning individuals ages 18+; provide additional funding to the organization or organizations proportionally based on caseloads.

The Working Group offers two (2) additional considerations (A&B) in meeting these six (6) recommendations:

(A) Incorporate prior study recommendations made to the Vermont Legislature.

In 2012, a different self-neglect working group established by the Vermont Legislature submitted a report to the legislature containing recommendations regarding self-neglect similar to some of those presented here. Following that report, a directed study in Vermont was conducted in 2014 and submitted with further recommendations. See Appendix D for a summary of the recommendations submitted to the Vermont legislature in 2012 by the self-neglect working group.

(B) Provide the funding necessary to appropriately address self-neglect.

The Working Group has determined that Vermont cannot meaningfully improve its response to self-neglect without directing additional resources to that end. This report specifies where such funding can and should be applied, and recommends potential funding mechanisms as well. The Working Group recommends that Vermont dedicate funding to support the provision of services to self-neglecting individuals proportionally (i.e., based on provider caseloads and outcomes). The Working Group recommends allocating funds to providers through state grants / RFPs.

Appendix A: Membership of the Self-Neglect Working Group

Act 156: https://legislature.vermont.gov/Documents/2020/Docs/ACTS/ACT156/ACT156%20As%20Enacted.pdf

The following table lists the individuals and their respective organizations, including at-large members not required by Act 156:

Joe Nusbaum	DAIL Commissioner's Designee		Sarah Launderville	Vermont Center for Independent Living
Conor O'Dea	DAIL Adult Services Division Director Designee		Michael LaMantia, MD or Janet Nunziata	UVM Center on Aging
Sarah Nussbaum	DAIL Developmental Disabilities Services Division Director Designee		(unfilled despite efforts to recruit)	Consumer appointed by DAIL Advisory Board
Trish Singer, MD	Department of Mental Health Adult Service Division		Lynne Cardozo	Consumer appointed by DMH Adult Program Standing Committee
Jamie Renner and/or Ben Chater	Vermont Attorney General's Designee		Bethany Drum	Consumer appointed by DDSD State Program Standing Committee
Meg Burmeister	Vermont Association of Area Agencies on Aging		Lisa Lambert	Elder Care Clinicians
Sean Londergan	Long Term Care Ombudsman/ Vermont Legal Aid, Inc.		*Additional members not outlined in legislative language*	
Ruby Baker	Community of Vermont Elders (COVE)		Hope Smith	DAIL Commissioner's Office

Jill Olson	VNAs of Vermont		Leslie Johnson, PhD.	DAIL Commissioner's Office
Lindsey Owen	Disability Rights Vermont		Kelly Greaves	DAIL Adult Protective Services
			Will Eberle	AHS Field Director
			Meg Polyte	Alzheimer's Association Vermont Chapter
			Erin Roelke	Vermont Association of Area Agencies on Aging

Appendix B: Vermont State statutes that address self-determination

Adult guardianship

14 VSA 3060: https://legislature.vermont.gov/statutes/section/14/111/03060
18 VSA 9301: https://legislature.vermont.gov/statutes/section/18/215/09301

Proceedings involving RFA's where the Plaintiff has a disability and an Interested Person files for the RFA on Plaintiff's behalf, and then the Plaintiff says s/he does not want to pursue the RFA

1. 33 VSA 6934: "If the petition is made by an interested person, notice shall be provided to the vulnerable adult and the court shall determine whether the vulnerable adult is capable of expressing his or her wishes with respect to the petition and if so, whether the vulnerable adult wishes to pursue the petition. If the court determines that the vulnerable adult is capable of expressing his or her opinion and does not wish to pursue the petition, the court shall dismiss the petition."
2. 33 VSA 6935: "The court may modify its order at any subsequent time upon motion by either party and a showing of a substantial change in circumstances. If the motion for extension or modification of the order is made by an interested person, notice shall be provided to the vulnerable adult, and the court shall determine whether the vulnerable adult is capable of expressing his or her wishes with respect to the motion and, if so, whether the vulnerable adult wishes to request an extension or modification. If the court determines the vulnerable adult is capable of expressing his or her wishes and does not wish to pursue the motion, the court shall dismiss the motion."

DMH involuntary commitment proceedings, and laws around involuntary treatment

- 18 VSA 7101(17):

"A person in need of treatment" means a person who has a mental illness and, as a result of that mental illness, his or her capacity to exercise self-control, judgment, or discretion in the conduct of his or her affairs and social relations is so lessened that he or she poses a danger of harm to himself, to herself, or to others:

(A) A danger of harm to others may be shown by establishing that:

(i) he or she has inflicted or attempted to inflict bodily harm on another; or

(ii) by his or her threats or actions he or she has placed others in reasonable fear of physical harm to themselves; or

(iii) by his or her actions or inactions he or she has presented a danger to persons in his or her care.

(B) A danger of harm to himself or herself may be shown by establishing that:

(i) he or she has threatened or attempted suicide or serious bodily harm; or

(ii) he or she has behaved in such a manner as to indicate that he or she is unable, without supervision and the assistance of others, to satisfy his or her need for

nourishment, personal or medical care, shelter, or self-protection and safety, so that it is probable that death, substantial physical bodily injury, serious mental deterioration, or serious physical debilitation or disease will ensue unless adequate treatment is afforded.

Power of Attorney

- 14 VSA 3508(b): “If the principal intends that the power of attorney become effective upon the principal's subsequent disability or incapacity, the power of attorney shall state that fact, and specify the manner in which the disability or incapacity is to be determined.”

Advance directives, and other laws around health care surrogates

- 18 VSA 9702
- 18 VSA 9706 (maybe 9707-09 too)
- 18 VSA 9731

The standard for law enforcement to take someone into protective custody

- 18 VSA 4810

Appendix C: Self Neglect Stakeholders Survey

Survey Purpose and Limitations

The Self-Neglect Stakeholders Survey was designed to solicit additional information and input from organizations who may work with self-neglecting Vermonters in order to better understand the scope of referral, screening, assessment, prevention and/or intervention practices currently utilized by organizations that serve vulnerable Vermonters. Additionally, several survey questions were included to assess understanding and use of the current definition of self-neglect.

The survey responses were primarily used as a source of additional information, and the following limitations prevented drawing specific conclusions from the responses:

- Respondents were not required to list their name or organization, so results could not be reliably filtered by organization type
- Survey questions were not validated
- Multiple members of individual organizations responded to the survey
- Multiple respondents skipped questions
- In order to improve survey response rate, several questions were designed as multi-select questions with pre-written responses. These types of questions may have shaped respondents' answers.

Because of the above limitations, the stakeholder survey was used primarily as a tool to solicit input from additional stakeholders. In some cases, individual respondents were contacted to provide more information to inform the information and recommendations in this report.

Survey Questions:

The Self-Neglect Stakeholder Survey contained the following questions:

1. Vermont Act 156, The Older Vermonters Act, defines the term “self-neglect” as follows (33 V.S.A. § 6203):“(A) ‘self-neglect’ means an adult's inability, due to physical or mental impairment or diminished capacity, to perform essential self-care tasks, including: (i) obtaining essential food, clothing, shelter, and medical care; (ii)obtaining goods and services necessary to maintain physical health, mental health, or general safety; or (iii)managing one's own financial affairs. (B) The term "self-neglect" excludes individuals who make a conscious and voluntary choice not to provide for certain basic needs as a matter of lifestyle, personal preference, or religious belief and who understand the consequences of their decision.” Does this definition align with how your organization defines self-neglect?
2. What, if any, modifications and/or changes would your organization suggest to the definition of self-neglect as outlined in statute by Act 156: The Older Vermonters Act (definition stated in question 1 above)? Please explain.
3. Does your organization work with individuals who display self-neglecting behaviors as defined by Act 156:The Older Vermonter’s Act?
4. If your organization does work with individuals who display self-neglecting behaviors as outlined by Act 156,The Older Vermonters Act, which services, if any, does your organization provide to address self-neglecting behaviors? (choose all that apply)

5. Does your organization use an assessment tool to identify self-neglecting behaviors in the people whom you serve?
6. If your organization uses an assessment tool to identify self-neglecting behaviors in the people whom you serve, please describe and/or identify the assessment tool. Please type "NA" if not applicable.
7. Does your organization make referrals to outside entities when a person whom you serve is identified as having behaviors, characteristics, and/or risk factors associated with self-neglect?
8. If your organization makes referrals for self-neglecting behaviors, to whom do you make these referrals(choose all that apply).
9. For your organization, which services are most effective for supporting individuals who engage in self-neglecting behaviors? Please provide a brief explanation.
10. Does your organization have operational efforts focused on the prevention of self-neglecting behaviors by the people whom you serve and/or older Vermonters more broadly?
11. If your organization has operational efforts focused on the prevention of self-neglecting behaviors, please provide a brief explanation of the operational efforts. Please type "NA" if not applicable.
12. What do you feel are the strengths, if any, of Vermont's efforts for prevention, identification, and intervention of self-neglecting behaviors in older adults?
13. What do you feel are the weaknesses, if any, of Vermont's efforts for prevention, identification, and intervention of self-neglecting behaviors in older adults?
14. What is your name?
15. What is the best email address at which to contact you?
16. What is the name of your organization?
17. In what county/counties does your organization operate (choose all that apply)?
18. Please briefly describe the populations served by your organization.
19. Which of the following age groups do/does your organization serve (choose all that apply)

Survey Response:

An invitation to complete the survey was sent by email to 161 individuals. Individuals were identified by members of the Self Neglect Work Group based on their affiliation with organizations who serve Vermonters who may exhibit self-neglecting behaviors. Recipients of the email invitation were also invited to forward the survey to other professionals in their networks who may work with self-neglecting individuals or have an interest in providing input about the current and future state of self-neglect services in Vermont.

There were 98 total responses to the survey. Of those, only 57 respondents provided the name of their organization. Because over 40% of respondents left this question blank, it is not possible to know specifically which organizations were not represented in this survey. However, the following organizations were listed by one or more respondents:

- Age Well

- Alzheimer's Association – Vermont Chapter
- Bayada Home Health Care
- Bennington County Coalition for the Homeless
- Benington Police Department
- Brattleboro Housing Partnerships
- Burlington Housing Authority
- Cathedral Square Corporation
- Central Vermont Council on Aging
- Champlain Housing Trust
- Community Connections at NVRH
- Gifford Health Care
- HOPE
- Mt. Ascutney Hospital & Health Center
- Northeast Kingdom Council on Aging
- Pathways Vermont
- Rutland Mental Health Services
- Rutland Housing Authority
- Support and Services at Home (SASH)
- Senior Solutions
- Shires Housing
- State of Vermont Agency of Human Services (AHS)
- State of Vermont Department for Disabilities, Aging, and Independent Living (DAIL)
- Southwester Vermont Council on Aging (SVCOA)
- The Community Restorative Justice Center, Inc.
- Vermont Center for Independent Living
- Visiting Nurses Association (VNA)
- Winooski Housing Authority