

Responding to Self-Neglect in Vermont

Department of Disabilities, Aging, and Independent Living

Executive Summary

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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. 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. 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.”

In 2013, 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. Data reflects the perspectives of 137 service provider survey respondents and 36 key stakeholder interviewees.

Scope and Severity

The scope of self-neglect is particularly challenging to ascertain. The majority of respondents indicated they were “*unsure*” or “*don’t know*” the number of self-neglect cases they are involved in each year. 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 information make this data difficult to interpret and should be evaluated cautiously.

- *There is a need for definitional clarity, more accurate reporting of self-neglect, and consistent documentation. This is not only important for the development and provision of services, but vital to the health and well-being of those involved.*

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 (85%) report that compared with the average workload, cases of self-neglect take more time.

Respondents identified the **greatest challenges to serving adults who are self-neglecting** as lack of desire for/refusal of services, inadequate access to and funding of services, cognitive and mental health issues, limited family and community connectivity, and lack of clarity on self-neglect/capacity determination. 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) education and training, 2) outreach, assessment, and service provision, and 3) enhanced community support and involvement.

EDUCATION AND TRAINING

- There is a *need for clarity around the reporting and referral process for suspected cases of self-neglect*.
 - Study findings clearly indicate a lack of clarity regarding self-neglect reporting. Respondent indicated, “*I don’t know where to report this*” and “*most go unreported unless life threatening.*”
- Service providers across the continuum of health and social services are in need of training to enhance the recognition of and response to self-neglect.
- Service providers and the general public would benefit from public education to help raise awareness about warning signs, resources and referral options.

OUTREACH, ASSESSMENT AND SERVICE PROVISION

- 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*.
 - Adequate outreach and assessment could significantly enhance coordination of care and efficient utilization of services.
- Case management services are consistently identified as an essential component of the response to cases of suspected self-neglect. Case managers play a crucial role in coordinating care and facilitating collaboration.
 - Nearly 95% of survey respondents reported it is *important to engage in interdisciplinary collaboration* with colleagues and providers from other organizations.
- 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. The majority of respondents (59%) agreed that “individuals identified as ‘self-neglecting’ usually have underlying, untreated mental health problems or cognitive impairment.”
 - Respondents expressed 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.*”

ENHANCED COMMUNITY SUPPORT AND INVOLVEMENT

- It is of primary importance that the public is informed regarding the nature of self-neglect and process for report, referrals, and response.
- It is clear that there is a *need for additional support for families and caregivers*.
 - 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.
- 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.
 - Community members are generally the concerned party that brings self-neglect to the attention to others. Providers can partner with community members to engage in both prevention and intervention efforts, however attention to and resources for training and support would be essential.

	First Step	Next Step	Areas for Future Exploration
Education and Training	<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
Outreach, Assessment and Service Provision	<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 Support and 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

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.