



Self-Neglect: Findings from the ADvancing States National Survey of Adult Protective Services

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Adult Protective Services**

Executive Summary

Adult Protective Services (APS) are social services provided by state and local governments and other nonprofits to older persons and/or adults with disabilities who are at risk of being abused, neglected, sexually assaulted, or financially exploited, or are experiencing self-neglect. A majority of APS programs respond to reports of self-neglect. Elder abuse and self-neglect are also referred to as adult maltreatment. The types of maltreatment investigated vary from state to state. APS is a program designed to serve people in need of protection and assistance and connection to social services and benefits. APS definitions, standards of practice, and eligibility requirements vary from jurisdiction to jurisdiction. In most states, APS serve populations 18 and older, while a few programs only serve older persons aged 60 and above. In many states, APS clients are referred to as “vulnerable adults”. This includes adults 18 and older with a significant physical and/or mental impairment. While APS support clients experiencing many different types of maltreatment, clients experiencing self-neglect is the most prevalent form of maltreatment reported. The prevalence of cases of self-neglect suggests a need for further exploration on this topic. The purpose of this brief is to describe the issue of self-neglect, discuss services needed for this population, and highlight what states are doing to address self-neglect. This issue brief highlights findings from ADvancing States’ 2022 National Survey of Adult Protective Services Programs.

Background and Methodology

The 2022 National Survey of Adult Protective Services Programs was designed to assess the current landscape of APS, with a special focus on people experiencing self-neglect. The number of individuals experiencing self-neglect in which the allegation has been substantiated is consistently higher than all other maltreatment types combined.¹ Given the significant percentage of APS clients experiencing self-neglect, the survey specifically asked questions to learn more about APS and self-neglect. ADvancing States surveyed state APS programs using a web-based survey instrument. The survey was disseminated to ADvancing States' state members, who were requested to forward it to the person responsible for APS in their state.² Depending on how the program is administered, some county APS programs provided assistance with the state agency response. The survey was in the field in March 2022, with follow-up to ensure responses from all 50 states and the District of Columbia.

What is Self-Neglect?

Self-neglect refers to an adult's inability, due to physical or mental impairment or diminished capacity, to perform essential self-care tasks such as obtaining essential food, clothing, shelter, and medical care; obtaining goods and services; or managing financial affairs.³ In understanding self-neglect and protective services, it is important to keep in mind that individual choice and autonomy are important values, and these values are highlighted throughout the field, including in the National Adult Protective Services Association's (NAPSA) Code of Ethics and the National Voluntary Consensus Guidelines. Using person-centered language aligns with principles valued by APS. Language used can have a profound impact on how others view older adults, adults with disabilities, and APS. As it relates to self-neglect, an example of person-centered language is people or clients at risk of or experiencing self-neglect. While the term self-neglect is used, there is recognition that the term may be inaccurate as sometimes self-neglect may happen as a result of systemic failures, rather than as a result of the individual.⁴ Additionally, some states are moving toward verifying the need for protective services for cases of self-neglect, though other states continue to characterize self-neglect as the person being their own perpetrator.

How Prevalent is Self-Neglect?

According to the National Adult Maltreatment Reporting System (NAMRS), in Fiscal Year (FY) 2021, the

¹ McGee, L. & Urban, K. (2022). Adult Maltreatment Data Report 2021. Submitted to the Administration for Community Living, U.S. Department of Health and Human Services.

https://pstrapiubntstorage.blob.core.windows.net/strapib/assets/2021_NAMRS_Report_2024_Final.pdf

² ADvancing States' members oversee the implementation of the Older Americans Act, and many also function as the operating agency in their state for Medicaid waivers that serve older adults and individuals with disabilities. Approximately one-half of ADvancing States members are responsible for administering Adult Protective Services.

³ Elder Justice Act. 42 USC Chapter 7, Subchapter XX, Division B: Elder Justice (2010).

https://www.ssa.gov/OP_Home/ssact/title20/2011.htm

⁴ APS TARC, 2024, An Overview of APS Self-Neglect Cases Using NAMRS Data.

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number of people with substantiated cases of self-neglect was higher than all other maltreatment types combined.⁵ This is consistent with previous years as well. Additionally, “self-neglect is the only maltreatment category where the percentage of substantiated allegations is higher than the percentage of unsubstantiated allegations.”⁶ In FY21, 59.1 percent of referrals for alleged maltreatment were accepted for investigation, and of these reports, 34.2 percent had a substantiated investigation. Of the reports accepted for investigation, the allegation types included: 50 percent self-neglect; 24.2 percent neglect; 24.2 percent exploitation; 12.7 percent physical abuse; and 1.5 percent sexual abuse (note there can be multiple types of allegations in an investigation). Notably, in FY21, 50 percent of allegation types were considered to be self-neglect. Since the start of the pandemic, there has been an increase in the percentage of allegations of self-neglect. Additionally, self-neglect cases increased during the early months of the pandemic. The prevalence of self-neglect suggests that clients are not adequately accessing or being connected to needed services. Services can support family, social, and community connections.

Furthermore, the 2022 ADvancing States survey asked states to describe the percentage of total APS clients served for what is categorized as self-neglect. The majority of respondents reported between 41 and 50 percent (figure 1). Of note, there were five states who indicated the total cases of self-neglect comprised between 51 and 60 percent of their cases, as well as five respondents who reported between 61 and 70 percent. This data demonstrates that people experiencing self-neglect comprise a large portion of APS cases.

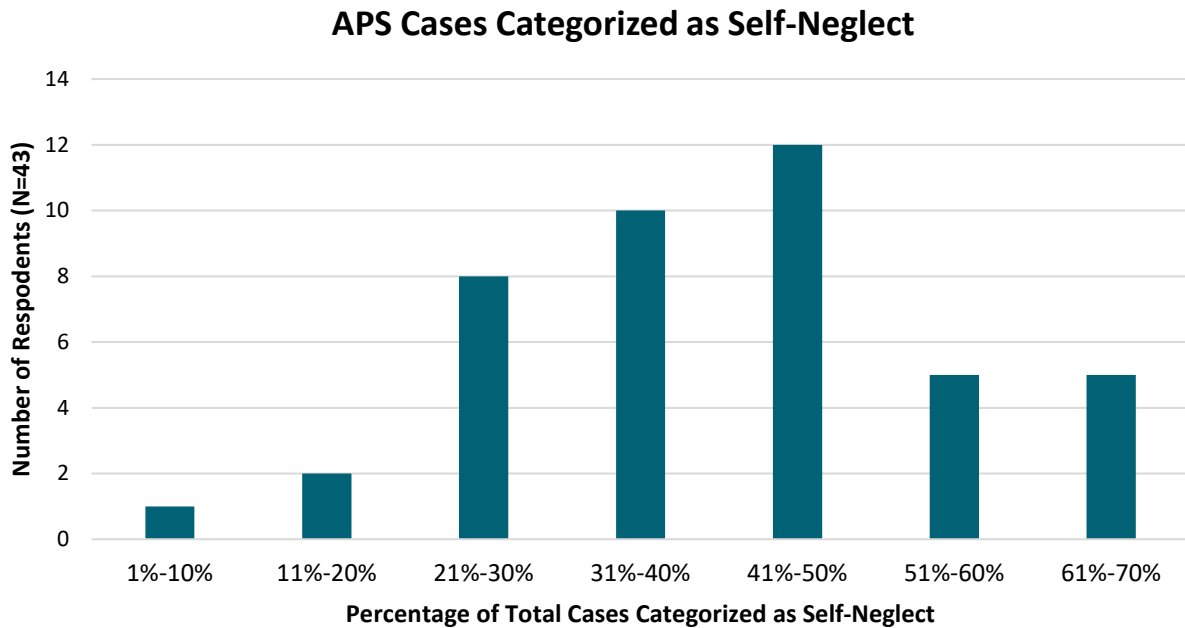
⁵ McGee, L. & Urban, K. (2022). Adult Maltreatment Data Report 2021. Submitted to the Administration for Community Living, U.S. Department of Health and Human Services.

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⁶ McGee, L. & Urban, K. (2022). Adult Maltreatment Data Report 2021. Submitted to the Administration for Community Living, U.S. Department of Health and Human Services.

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Figure 1



Description: Figure 1 is a bar chart of state responses of total APS clients served for what is categorized as self-neglect. There was a total of 43 state respondents. The top response, with 12 states, was between 41 and 50 percent, followed by ten states reporting between 31 and 40 percent, and eight states reporting between 21 and 30 percent.

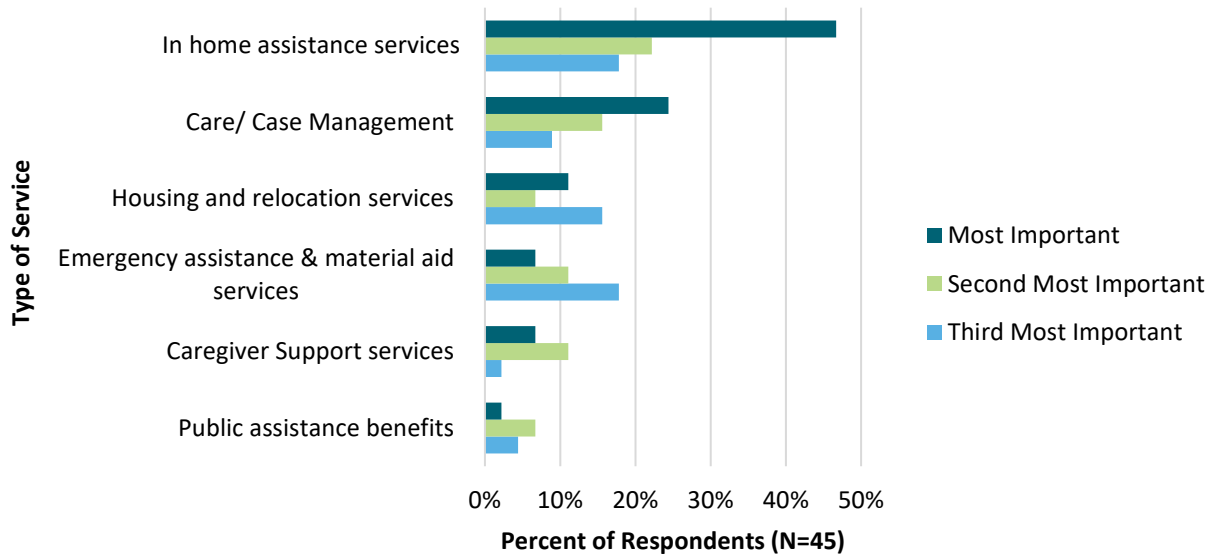
What Services Do Persons Experiencing Self-Neglect Need?

To better understand the needs of clients experiencing self-neglect, the 2022 ADvancing States survey asked participants to rank the most needed services for these clients, regardless of availability (figure 2). By far the most needed service, reported by 47 percent of respondents, was in-home assistance services (such as bathing, dressing, grooming, medication management, supervision). The next most needed service was care/case management, reported by 24 percent of respondents. In-home assistance services were also the highest ranked for second and third most important services needed (along with emergency assistance and material aid services for third most important). Additionally, as noted in NAMRS, individuals experiencing self-neglect receive services more often than any other type of maltreatment, demonstrating the importance of services for clients experiencing self-neglect.⁷

⁷ McGee, L. & Urban, K. (2022). Adult Maltreatment Data Report 2021. Submitted to the Administration for Community Living, U.S. Department of Health and Human Services.
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Figure 2

Top Six Most Needed Services for Clients Experiencing Self-Neglect



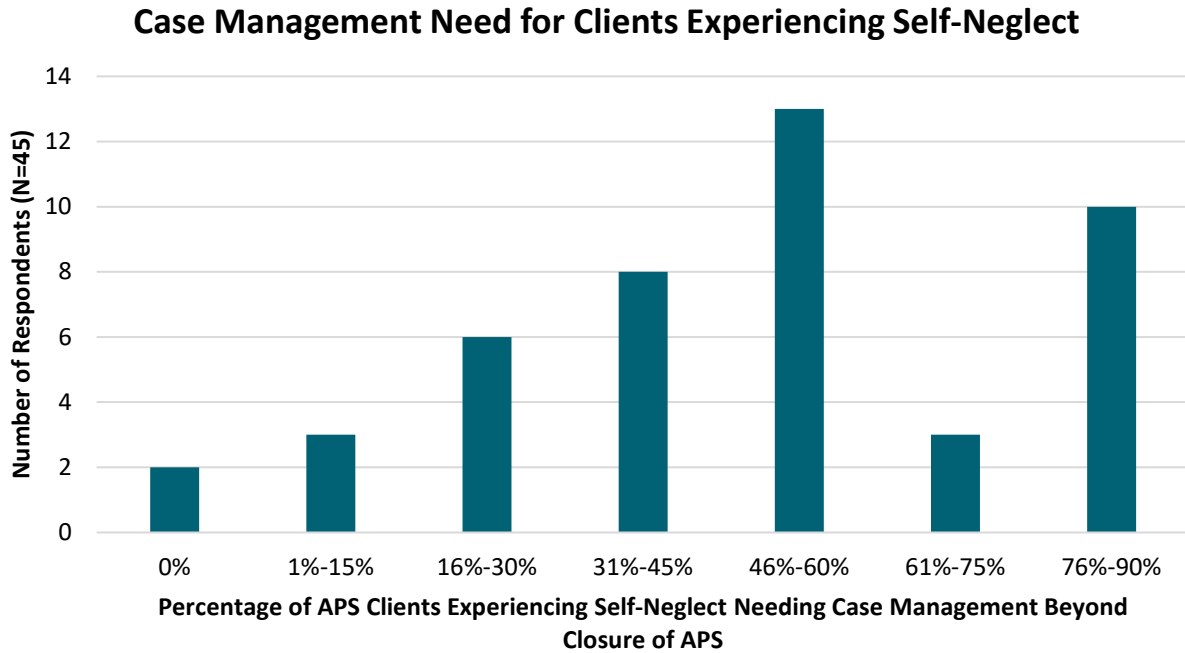
Description: Figure 2 is a bar chart of the top six most needed services for clients experiencing self-neglect (N=45). The top six most important services reported include in-home assistance, care/case management, housing and relocation services, emergency assistance & material aid services, caregiver support services, and public assistance benefits.

Supportive services, such as case management and in-home assistance, help people perform self-care, maintain health, and manage financial affairs. These critical services can prevent people from returning to APS. Recurrence is when persons return to APS after their cases have been closed. An APS client outcomes study found that, “self-neglect was associated with the greatest risk of recurrence across maltreatment types.”⁸

Furthermore, respondents were asked to describe the percentage of APS clients experiencing self-neglect who need case management beyond the closure of APS (figure 3). For **clients experiencing self-neglect**, the most reported response, with 13 respondents, was between 46 and 60 percent. Notably, ten respondents reported between 76 and 90 percent of clients experiencing self-neglect needed case management beyond closure of APS. In comparison, the most reported response for **all APS clients** who need case management beyond the closure of APS, with 18 respondents, was between 16 and 30 percent (figure 4).

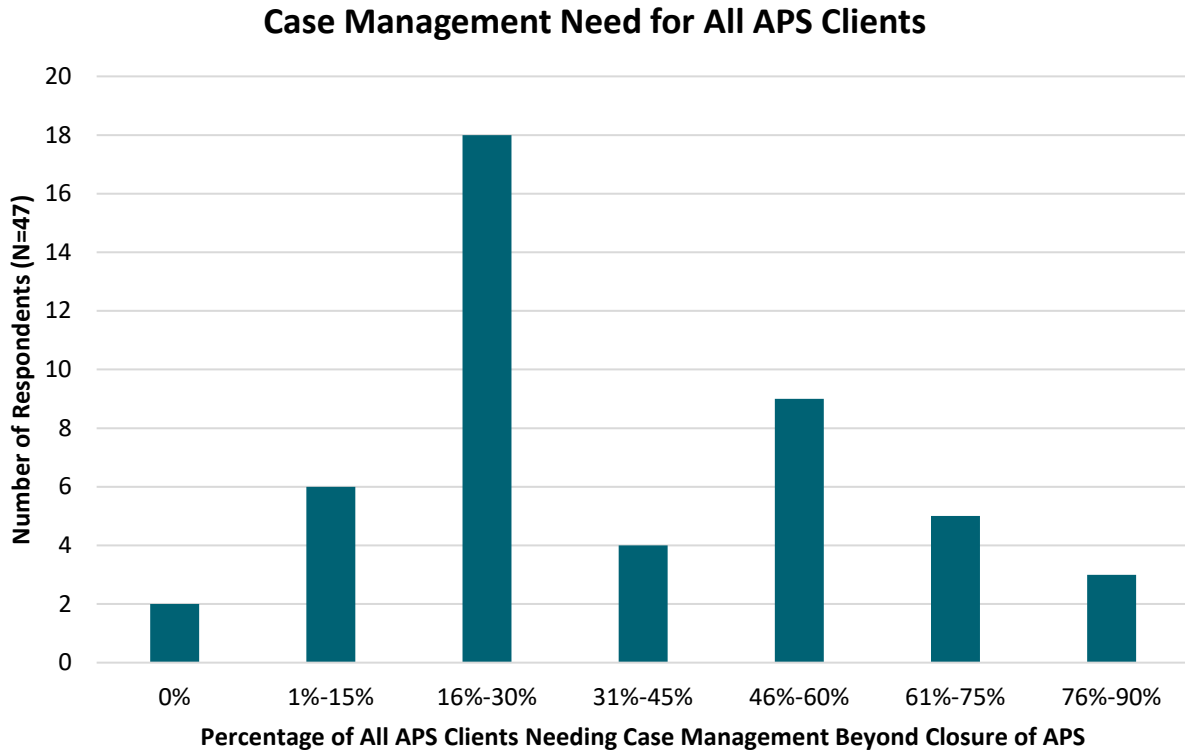
⁸ Gaeta, Raphael; Leopold, Anne; Twomey, Mary; Gassoumis, Zach; & Lovegrove, Peter. The Impact of Adult Protective Services on Client Outcomes: Findings from a Multi-State Study. <https://www.napsa-now.org/wp-content/uploads/2023/02/NAPSA-R2P-Brief-Final.pdf>

Figure 3



Description: Figure 3 is a bar chart representing responses (N=45) for the percentage of APS clients experiencing self-neglect who need case management beyond the closure of APS. The most reported response, with 13 states, was between 46 and 60 percent, followed by ten states reporting between 76 and 90 percent, and eight states reporting between 31 and 45 percent.

Figure 4



Description: Figure 4 is a bar chart representing responses (N=47) for the percentage of all APS clients who need case management beyond the closure of APS. The most reported response, with 18 states, was between 16 and 30 percent, followed by nine states reporting between 46 and 60 percent, and six states reporting between one and 15 percent.

APS is designed for emergent problems and not long-term support, though characteristics of self-neglect and outcomes demonstrate the condition of self-neglect can be chronic and not acute. Case management beyond the closure of APS is one tool that can provide extended support that is often needed for individuals experiencing self-neglect.

What is the Role of APS and the Aging and Disability Network?

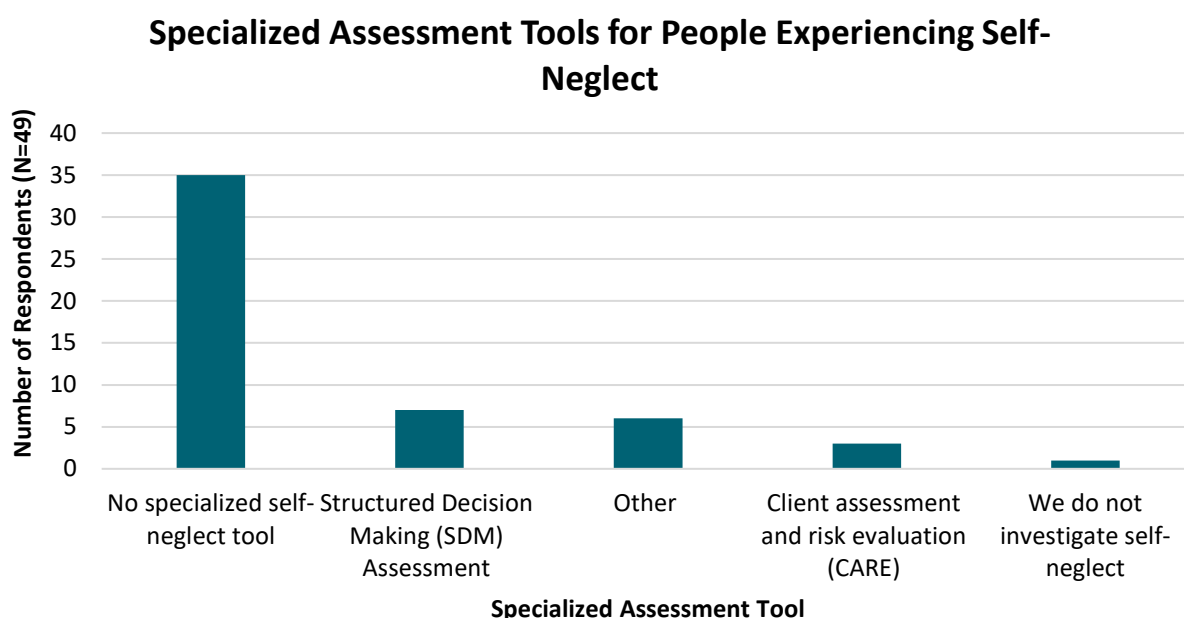
Adult Protective Services

When the ADvancing States survey was administered in 2022, almost all states, 96 percent, reported providing services to people experiencing self-neglect. Two states reported their APS program does not provide protective services to people experiencing self-neglect. Of these, one respondent said that Area Agencies on Aging (AAA) provide protective services support, and the other participant shared that

another state agency program provides assistance.⁹

To identify people experiencing self-neglect, there are specialized assessment tools available that some APS programs are using. However, the majority of respondents, 35 states, reported that they are not using a specialized self-neglect assessment tool (figure 5). Seven states shared that they are using the Supported Decision-Making (SDM) Assessment, six states indicated other, three states reported using the Client Assessment and Risk Evaluation (CARE), and one state said they do not investigate self-neglect. While many states do not use specialized assessment tools for people experiencing self-neglect, these tools are available to states and can support the APS programs in identifying the unique needs of people experiencing self-neglect.

Figure 5



Description: Figure 5 is a bar chart (N=49) representing responses for specialized assessment tools used for people experiencing self-neglect. Thirty-five states do not use a specialized self-neglect tool, seven states use the Structured Decision Making Assessment (SDM), six states use other, three states use the Client assessment and risk evaluation (CARE), and one state does not investigate self-neglect.

As discussed, services are often needed to support clients experiencing self-neglect. APS assists individuals in obtaining necessary goods and services to support their physical and mental well-being. APS may provide services such as case management, or may refer individuals to necessary services and supports within the aging and disability network or other organizations. While some programs may still conduct an investigation for cases of self-neglect, others are moving toward assessment. This change in approach includes addressing cases of self-neglect by focusing more on services, engagement, and client

⁹ Please note that the status of providing services to people experiencing self-neglect at the time of this issue brief and the status at the time of the survey are different. For example, one of the states that reported no to providing services to people experiencing self-neglect, has since passed legislation to move responsibilities for cases of self-neglect from the state unit on aging to APS.

participation and collaboration, as opposed to a traditional investigative approach.

The Aging and Disability Network

The aging and disability network provides valuable resources and services that can support clients upstream before the risk of self-neglect becomes acute. This network is comprised of local, state, and national organizations that support older adults and/or people with disabilities. Examples of services and supports include long-term services and supports (LTSS) counseling, peer support, information and assistance, home-delivered meals, homemaker assistance, health screening, transportation, assistive technology, and others.¹⁰ Among other roles, community partners may: make referrals to APS; provide services to APS clients; promote person-centered practices; identify needed services and gaps; advocate for self-determination; support decision-making; and reduce guardianship referral. APS' collaboration with other organizations can improve the care and support for people experiencing self-neglect.

What are States Doing in Response to Clients Experiencing Self-Neglect?

States are responding to the large number of cases of clients experiencing self-neglect by piloting and implementing innovative approaches in response to the needs of these clients. Several states, such as Colorado, Kentucky, Minnesota, and Oklahoma are approaching cases of self-neglect by focusing more on services, engagement, and client participation and collaboration, as opposed to a traditional investigative approach to determine whether maltreatment has occurred. While some states may not have labeled their efforts to approach cases of self-neglect differently, Colorado has described their new approach as an Alternative Response Pilot and more information about their pilot program is featured in the profile below.

¹⁰ Administration for Community Living (2018). Aging and Disability Networks. <https://acl.gov/programs/aging-and-disability-networks>

Colorado's Approach to Self-Neglect: The Alternative Response Pilot

In Colorado, APS is administered at the county level, and the state, through the Colorado Department of Human Services (CDHS), provides oversight, monitoring, and training to the county-based workforce. Statewide, 46 percent of substantiated cases are categorized as self-neglect, the highest percentage of maltreatment type for Colorado. In recent years, the Colorado APS program has established a vision to prioritize innovative, person-centered APS practices. One example of their vision in action is the launch of their Alternative Response (AR) Pilot in January 2023, which allows a pilot group of 15 counties to explore the feasibility and outcomes of a model that allows certain APS cases, including self-neglect, to be approached differently than a traditional investigative approach.

Background & Model

Beginning around 2018, county APS representatives in Colorado began exploring how they could respond differently to certain APS cases, such as self-neglect. Efforts from the counties led to Senate Bill (SB) 21-118, signed into law in June 2021. This legislation assigned CDHS to develop and implement the Alternative Response Pilot and secure a 3rd-party evaluator to conduct a feasibility study over a 2-year implementation period (2023-2024). CDHS must report evaluation outcomes to the Colorado General Assembly in 2025 and 2026. At that time, legislators may decide whether to authorize the pilot to continue, expand, or be terminated.

The pilot provides a dual-track model in which participating counties tailor their response method to the type of report they have received, recognizing that the impacts and outcomes of traditional investigative methods and findings are not always appropriate for certain circumstances. The model creates an alternative response option for allegations of self-neglect or mistreatment considered low-risk. The alternative response has two key differences from the traditional response: (1) initial visits are not required to be unannounced, and (2) a traditional finding is not made concerning the alleged maltreatment or self-neglect.

In this pilot, cases are assigned to the Alternative Response Track (AR) or the Traditional Response Track (TR). All cases of self-neglect are assigned to the AR track. In collaboration with county partners, CDHS developed regulatory parameters that outline which types of allegations may be considered for AR track assignment, and which types are excluded from AR track assignment.

Learnings to Date

While the AR pilot is applicable to multiple types of allegations, its application to self-neglect is of particular interest. Around 54 percent of cases assigned to the AR track are allegations of self-neglect. The AR track allows for cases of self-neglect to be approached in a way that may encourage more client participation and rapport building than a traditional investigative approach.

In developing and implementing this pilot, collaborating and fostering a foundation of trust and respect between the state, counties, and public stakeholders has been critical to its success. CDHS shared that throughout the process, it has been important to ensure that everyone involved has understood the vision of the pilot and that there has been genuine ongoing collaboration. The counties drove the initial interest in developing this pilot. Once it passed in the state legislature, CDHS was tasked with rule setting, leading, and facilitating the pilot, all of which require consistent and comprehensive communication with county APS programs. The state and counties created an atmosphere where partners were open to hearing from one another about what was both working and not working. This experience has helped the state and the counties build an even stronger relationship, as the pilot has created new avenues for working together. Together, the state and counties have developed a new approach which is at the forefront of innovation in the field of Adult Protective Services. Ultimately, the state, counties, and partners always come back to the shared goal that if the pilot is successful, they will see the benefits bear out in their clients' lives.

Conclusion

The prevalence of self-neglect compared to all other maltreatment types highlights the complex nature of the experiences of people experiencing self-neglect as well as the need for greater access and connection to services. Self-neglect is an issue that may require long-term support. States report that services such as in-home assistance and case management are needed for cases of self-neglect. APS, in collaboration with other organizations, provide services, supports, and connections that can help individuals experiencing an inability to care for themselves. Recognizing the complexity of self-neglect, states are exploring new ways of approaching these cases that are collaborative and person-centered, such as verifying a need for protective services.