

Self-Neglect Knowledge, Policy, Practice & Research: Realities & Needs

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Table of Contents

| | |
|---|----|
| Executive Summary..... | 3 |
| Introduction..... | 4 |
| Activities and Accomplishments..... | 5 |
| Measurable outcomes..... | 5 |
| Challenges faced and actions taken..... | 12 |
| Project Impact..... | 15 |
| Lessons Learned..... | 17 |
| Future Work..... | 24 |
| Significant Project Partners..... | 24 |
| Key Publications and Communications Activities..... | 25 |
| Summary and Recommendations..... | 32 |
| Appendices..... | 36 |
| A. Master Bibliography for Adult Self-Neglect Literature Review..... | 36 |
| B. Tables - Review of the Self-neglect Research Literature Key Findings.... | 43 |
| Table B1. Social Determinants and Correlates of Self-Neglect | |
| Table B2. Self-neglect Outcomes and Healthcare Utilization | |
| Table B3. Cognition, Capacity and Mental Health | |
| Table B4. Studies of Specific Self-neglect Behaviors | |
| Table B5. General Studies of Self-neglect | |
| Table B6. Psychometric Assessments of Self-neglect | |
| Table B7. Hoarding as a Form of Self-neglect | |
| C. Systematic Literature Review - Journals that Published Articles..... | 48 |
| D. 2017 Self-Neglect APS (SNAPS) Program Assessment..... | 50 |
| E. SNAPS Tables of Key Findings..... | 56 |
| F. Selected Findings APS Site Visits to Explore Innovations..... | 62 |

G. APS Case Assessment Tools Survey.....68
H. 2019 Tools Survey - Key Findings.....76
I. Tools Expert Panel Bios.....84
J. Examining the State Definitions of Self-Neglect.....86
K. Table of State APS-Tribal Collaboration.....89
L. Staff and Consultants - Project Year-One.....94

Executive Summary

Goal: Professionals in the fields of sociology, mental health, public health, medicine, social work, anthropology, and Adult Protective Services (APS) collaborated to explore self-neglect. The goal was to review 1) Scientific studies, 2) APS case reports, and 3) APS program response to self-neglect to identify gaps in knowledge, practices, and services. **Methods:** We used systematic review, national survey and expert panel methodologies to collect and summarize data on 1) 20-year self-neglect literature findings, 2) APS program operational, budgetary, referral and service-delivery data, 3) innovative APS self-neglect program practices, 4) APS case assessment tools. **Major Findings:** The scientific literature is mostly characterized by observational studies assessing social determinants of self-neglect without the ability to infer causality. Common social determinants are functional or cognitive limitations, preventable health problems, insufficient social resources, depression, and substance abuse. Outcomes include hospitalization and readmission, hospice and nursing home use, early mortality, and abuse by others. Fear, social isolation, and depression inhibit service acceptance. Inadequate research informs etiology and intervention. Insufficient APS data systems limited case specific research. Case assessment tools lacked psychometric support for appropriateness and usefulness for assessing client problems and intervention planning. **Recommendations:** The findings suggest the need for: 1) more funding of self-neglect and APS intervention and outcomes-focused research, 2) enhanced APS program data systems for reporting and research, 3) developing and implementing psychometrically supported APS-specific case assessment tools, and 4) training and supervision of APS staff in the appropriate use and limitations of assessments; especially those with clinical implications.

Introduction

This macro-level project has considered the complex phenomenon of self-neglect from the vantage points of both research and practice. Self-neglect is the most frequently reported allegation to APS programs across the nation. Despite this, only 73 relevant studies were published in the U.S. over the 20-year period of the project literature review. Self-neglect confers harmful consequences, including increased mortality, on those afflicted. Frequently, those who self-neglect fail to grasp the need for or benefit of intervention and refuse offers of assistance. Of interest and promise, a Texas study (Booker et. al., 2017) revealed that among self-neglecters who did accept APS services, 75% reported, at minimum, satisfaction with the services received. This study holds promise for the work of APS and collaborating services and professionals who struggle to engage self-neglecting vulnerable adults in careful assessment, intervention planning, and service acceptance. This project has pulled together relevant self-neglect information and drawn attention to some of the existing gaps in the current knowledge base and practice efforts. It is our hope that the lessons learned and recommendations offered will help to move APS practice and research forward to better equip APS professionals and their collaborators to understand and meet the needs of vulnerable adults suffering from self-neglect.

Activities and Accomplishments

1. What measurable outcomes did you establish for this project and what indicators did you use to measure performance? To what extent did your project achieve the outcomes?

I. Measurable outcomes established:

A. Comprehensively explore existing self-neglect research and literature

1. We conducted a systematic review of the self-neglect literature published within the U.S., over the last 20-years focusing on a) research findings, practice approaches and policy issues and b) tools to measure or assess characteristics of people who self-neglect and their self-harming behaviors and consequences.

2. Meta-analysis was considered a possible approach for combining similar studies and quantifying associations between self-neglect and social determinants and outcomes if determined feasible.

B. Characterize and compare APS program responses to self-neglect

The project conducted “Self-Neglect APS (SNAPS) Program Assessments” of every state program. We assessed state-by-state self-neglect policies and practices, innovative approaches, collaborations with other organizations, case assessment tools utilized, and aggregate data regarding self-neglect reports, investigations, substantiations, interventions, repeat reports, and case outcome data. APS program participation in research and multi-disciplinary efforts was also be assessed.

C. Identify innovative self-neglect practices, including collaborations between APS programs and community agencies.

Utilizing SNAPS results, we identified APS programs employing innovative approaches or collaborations to prevent or respond to self-neglect as well as programs that demonstrate better-than-average success in handling self-neglect. We selected three (3) such programs and visited them to learn about their innovations to inform effective approaches to prevent, investigate, and intervene in self-neglect.

D. Present findings to multi-disciplinary elder abuse/self-neglect/APS experts for consideration

We conducted a mini-Think Tank involving elder abuse/self-neglect experts from relevant fields to review and consider our confluence of findings and their implications for research, policy, and practice.

II. Indicators used to measure performance:

- A. Was the work that was planned to achieve the measurable outcomes undertaken?
- B. To what degree was the planned work completed?
- C. Are findings from each step of the planned work available?
- D. Have findings from each step been presented to colleagues and others to inform the field?
- E. Are additional dissemination methods underway now that the project is in its final stages?

III. Measurable outcomes accomplished - Applying the above indicators to measure performance, we have achieved our intended outcomes:

- A. **We have comprehensively explored the existing self-neglect research and literature by conducting a systematic review of the published research on adult self-neglect.** We used the following key words and phrases to guide the review: adult self-neglect, adult protective

services, self-determination, Diogenes syndrome and hoarding. We conducted a search using the Fordham University and Wayne State University e-libraries. The project team sought and identified additional publications to include. Databases used included: Pub med, Soc Index, EBSCO host (psychology and behavioral science), CINAHL (Cumulative Index to Nursing and Allied Health Literature), Google Scholar, Lexus Nexus, Psychoinfo, and Fordham Discovery (composite database). Consistent with our established search inclusion criteria, studies conducted in the U.S., published between 1996-2017, met accepted standards for qualitative and/or quantitative research methods, and published in a peer-reviewed journal were included. Guiding questions utilized for the search were: 1) What implications for policy, practice and research relevant to Adult Protective Services are included in the existing self-neglect literature? and 2) How can existing self-neglect literature inform and promote evidence-based Adult Protective Services practice? One team member identified articles that appeared to meet the above criteria then abstracts were sent to a second team member for review and inclusion decision. When questions or disagreements arose between the two primary raters, a third team member reviewed the article under consideration (blind of the two raters' decisions) and made a recommendation as to inclusion. Only articles written in English were included. We carefully reviewed the abstract from each selected study to confirm inclusion decisions. Then PDFs of complete articles were obtained, maintained in a central storage location, and reviewed by the entire study team. Slightly more than 3,000 seemingly relevant articles were identified through the data base search, but after closer review, only 193 were identified as relevant for the project. After further review, 73 were selected and included in the next stage of analysis. All 73 are listed in the

bibliography of included research articles (**Appendix A**). Tables conveying key literature review findings are provided in **Appendix B**. Journals that published the selected and reviewed articles are listed in **Appendix C**. We determined that a meta-analysis of self-neglect research findings was feasible given the review findings. The reasoning to forgo a meta-analysis was based on the vast differences in study methodologies, definitions of outcomes, measurement of outcomes and samples used in the self-neglect studies. The authors felt that trying to establish an effect size for any of the outcomes or associated factors, given the limitations stated above, could be misleading and do more harm than good for understanding self-neglect and its associated social determinants. Instead, the authors chose to focus on the constancy of associations to identify links between self-neglect and social determinants of health; an outcome more suited for systematic review.

B. We have illuminated APS response to self-neglect and comparatively analyzed APS programs. We conducted “Self-Neglect APS (SNAPS) Program Assessments” of APS programs. The SNAPS Questionnaire (**Appendix D**) was developed, piloted, and revised. Early in 2017 it was electronically disseminated via “Survey Gizmo,” a web-based software program, to all APS state and territory program administrators with an explanation of the project and how the findings would be used. A pdf copy was provided to enable preparation of responses. Project Team member Andrew Capehart selected and managed the use of the software and the resulting database which was saved and protected. Ramsey-Klawnsnik and Capehart consistently reviewed incoming SNAPS questionnaire responses to analyze trends, ensure questions were answered as completely as possible, and conduct “data-cleaning” via needed follow-up inquiries. During this period, members of the NAPSA board of directors and Regional Representatives contacted their

state APS administrator colleagues to encourage their participation in the survey. By May 2017, 54 completed SNAPS questionnaires were received yielding a 100% response from all 53 state APS programs. (PA and MA each have two statewide APS programs that separately handle elder and younger vulnerable adult abuse.) Guam also completed the SNAPS questionnaire reporting only 13 self-neglect cases handled during FY '16. The U.S. Virgin Islands and Puerto Rico (the two other U.S. territories that operate APS programs) were unable to complete the SNAPS questionnaire due to infra-structure limitations, notably insufficient staff and data-collection systems. However, both provided qualitative information regarding their APS programs. Of the 53 state APS programs, 49 responded affirmatively to the question, “Are reports of alleged self-neglect (SN) investigated by your program?” (As of July 2018, 50 of the 53 state APS programs investigate self-neglect reports.). Formal quantitative and qualitative analysis of the SNAPS questionnaire data submitted by the 49 states handling self-neglect at the time of the survey has been completed to determine overall trends and identify policy, practice, and research implications as well as interesting correlations and associations (**Appendix E. SNAPS Tables of Findings**). Given that only 13 cases of self-neglect was received from the U.S. territories, the statistical analysis only included data received from the 49 state programs. We also compared the SNAPS questionnaire findings to our literature search findings where meaningful. We have completed multiple conference presentations to disseminate selected SNAPS questionnaire findings (see details below) and are we are preparing a manuscript for submission to a peer-reviewed scientific journal.

C. We have explored innovative APS practices and collaborations to respond to self-neglect.

More than one-quarter (N=15) of the state APS programs responded affirmatively to SNAPS

question E1 (page 6, Appendix D): “Do you use one or more innovative practices to prevent or respond to self-neglect cases?” A follow-up discussion sought to determine the nature of innovative practices employed. Responses were analyzed to identify innovative practices and collaborations designed to prevent and remediate self-neglect. Some were quite vague (our innovative practices “vary from county to county”) or described practices that, while innovative for the involved program, have been standard in many locales for years (i.e. we collaborate with law enforcement officers to do well-being checks on self-neglecting clients). We conducted a follow-up site visit with four programs that reported innovative practices or collaborations. We designed these meetings to gather more in-depth information. We contacted each program to request permission to conduct a site visit to learn about the identified practice(s). During 2017, project personnel visited Florida, Texas, and Washington, DC APS programs for data-collection. We also conducted a site-visit with the St. Regis Mohawk Tribal APS Program in upstate New York to learn about their collaboration with the NYS APS program. Selected site visit findings are summarized in **Appendix F**.

D. We have presented findings to multi-disciplinary elder abuse/self-neglect/APS experts for consideration via multiple events (detailed below) and are continuing our dissemination efforts.

E. Additional measurable objective established and achieved

In addition to achieving the measurable objectives identified during our project planning, we undertook another objective in project year-three: **update and expand our APS case/client assessment tools findings**. Analysis of our 2017 SNAPS survey data regarding tools used by APS programs, in conjunction with our literature search findings, resulted in concerns regarding

tools and scales used by APS programs to assess self-neglecting clients and guide service delivery. Among the 49 state APS programs that handled self-neglect, 76% (N = 37) responded affirmatively to: **“Does your APS staff use screening or assessment scales, tests, or similar tools (for any purpose) in self-neglect cases? (These may also be used in other types of cases.)”** Programs that responded affirmatively were asked to identify tools used. Thirty-five (35) programs specified their tools. Most stated that their tools are *not specific* for use in self-neglect cases but are used for *all* APS cases. Some commented that their tools are not in standard use across their state. In conclusion, **SNAPS findings revealed a lack of specificity and standardization of case assessment tools used by APS programs in self-neglect cases, but furthermore, a lack of specificity and standardization of tools used in ALL cases handled by APS programs (abuse, caregiver neglect, exploitation).**

Many of the case assessment tools APS programs reported using were not developed for APS use but rather for geriatric clinical use. Examples include the SLUMS (St. Louis University Mental Status), the Mini-Mental Status Exam, and the Geriatric Depression Scale. This raises ethical and practice questions: Are these clinical assessment tools appropriate for APS caseworker/investigator administration, scoring, and interpretation? Is sufficient training provided to APS caseworkers/investigators in the correct application, scoring, and administration of these tools? Is the use of these clinical assessment tools by APS staff promoting accurate client/problem assessment and effective casework? Review of 2017 SNAPS findings also suggested that those case assessment tools that were developed specifically for APS use were, for the most part, developed by the state programs using them, or, if you will, “homemade.” This raised questions regarding the reliability and validity of the tools used. During our final project

year, we more extensively analyzed this case measurement tools data. Based upon this information, we developed, piloted, revised then administered a mini-survey to APS programs nationwide to update our findings regarding tools employed in self-neglect, but also other APS cases, the “**2019 APS Case Assessment Tools Survey**” (**Appendix G**). Survey findings were analyzed using standard qualitative and quantitative methods. Key findings are contained in **Appendix H**. We convened an expert panel (**Appendix I**) to review, discuss, and interpret our findings and contribute to APS policy, practice, and research recommendations that will emanate from this project.

2. What, if any, challenges did you face during the project and what actions did you take to address these challenges?

I. Challenge: The inability of many state APS programs to accurately report aggregate data for FY ‘16 Report and Case Information (page 4 of 6, Appendix C. SNAPS 2017 Questionnaire) was quite surprising, revealing, and significant. This resulted in limited data-analysis, reporting and clearly identifying certain correlations among APS program variables. Unfortunately, many questions relating to the numbers of self-neglect reports screened in, substantiated, etc. had significant missing data. When combined with some of the other variables such as program budget, the sample size for the correlations dropped well below $n = 30$ which is a minimum number for the reliability of correlational data.

Action taken: We reviewed the data for patterns and extent of missing data to determine the most appropriate course of action for the analysis. Given the proportion of missing data it is not statistically advised to impute the missing values due to imposed bias and false confidence in the results. Therefore, the best approach was to conduct limited bivariate analyses and describe the

constituent programs that make up those samples as well as provide transparency regarding the limitations and generalizability of the results.

II. Challenge: A struggle throughout the project was having insufficient time and funding to carefully and fully complete all the project components of this first national attempt to study self-neglect and APS responses to it. The project was initially designed with a two-year timetable. This was revised to a one-year project in the fall of 2016 when only one-year funding was awarded with the possibility of receiving second year funding if available. The project proceeded at a very fast-pace throughout the first 12 months while we had funding to support a full project team. At the close of year one, we were informed that year-two project funds were not available.

Action taken: Having been frugal with our budget during year-one, we then used our remaining funds and worked under a No-Cost Extension throughout year-two. Almost all paid project consultants were “let go” due to the lack of funds, and the project carried on with only the Project Director and one paid consultant, Dr. Burnett, our needed statistician and self-neglect expert, to continue the work. Additionally, Carol Dayton, who provided project services pro bono as part of the NAPSA matching funds, continued her important work with us. For another project extension to conduct continued project activities in year-three, we were awarded a small additional amount of funding which was funneled through the WRMA APS TARC. In addition, we still had a small amount of our original year-one funding remaining and used this for the year-three No-Cost Extension to conduct the updated APS tools survey.

III. Challenge: Having some of our 3rd year ACL funding funneled through WRMA to NAPSA created a significantly more cumbersome process for clarifying ACL expectations and

requirements and for communicating with ACL than the process in place for the first two years of our grant. During project year one and two, Project Director Ramsey-Klawnsnik collaborated with and reported directly to our ACL Project Officer Gurley Parry. This switch to some project funding being funneled through WRMA was accompanied by a second major process change: a change in NAPSA leadership. Project communication then occurred in a more cumbersome and indirect pathway: Ramsey-Klawnsnik needed to communicate to NAPSA Executive Director Lori Delagrammatikis who communicated with WRMA Executive Director who communicated with ACL. Ramsey-Klawnsnik continued to meet monthly with Project Officer Parry to discuss the project as required. In some situations, inconsistent instructions were received from the two sources of information: directly from ACL via Ms. Parry and that information filtered from WRMA to NAPSA ED to Project Director. The WRMA funding also resulted in the Project Director being required to complete this project final report by the final day of the grant project and not having the typical 90 days post project-close provided by ACL to Project Directors to complete all reports and deliverables. This effectively and significantly short-changed the timeline for completing important and necessary project work. The Project Director was not informed of this loss of the 90 days to complete project reports and deliverables until very late in the project, as it neared the end of the project period, which created a significant hardship.

Action taken: The final project report was prepared under much less than sufficient circumstances and time constraints.

3. What impact do you think this project has had to date? What are the lessons you learned from undertaking this project?

I. Project Impact:

A. Over-all impact: The project team has made presentations at NAPSA Conferences (detailed below) beginning in 2017, highlighting information about what are the most frequent and often the most challenging cases for APS staff and allied professionals. It is significant to acknowledge and affirm the complexity of the problem, the variations across the country in response, and the ethical dilemmas encountered. The literature review provided context for the difficulties encountered in law, protocols and the wide range of conditions found when investigating allegations of self-neglect. The review of the legal definitions of self-neglect documented the complex task of defining when the government has the responsibility of intruding into a person's life to verify if they are capable of providing for their own care. One state has chosen not to do so at all.

Another has decided to do so only for its older population but not for the 18-59 disabled. Most states (74%) mandate an investigation of self-neglect. The impact of recognizing self-neglect as a unique category among the complex array of protective service allegations and investigations provides the opportunity to convey the importance of protecting the rights of the vulnerable adult along with recognizing the possibility of life threatening circumstances. An important impact is making clear the importance of providing the APS staff with skills needed to address ethical challenges, to engage clients who are isolated and often refuse help, and to place high value on sufficient screening tools to assess mental status and the need for sophisticated mental capacity testing to evaluate decision-making. Legal interventions require evidence that the person is incapable of making a reasonable decision re: self-care (e.g. for adult protective service

orders) or incompetent based on medical evaluation and a legal outcome of guardianship. Valid and reliable mental status evaluation is critical to these outcomes.

B. The available information regarding specific APS program policies, procedures, and services across the country has been expanded, both in regard to handling self-neglect cases and in general, and are detailed in the table in Appendix E. SNAPS Tables of Findings.

C. We have amassed knowledge regarding key correlations and associations between certain APS policies/procedures and service outcomes (detailed below). This knowledge builds a foundation for continuing APS and vulnerable adult maltreatment research. Furthermore, conducting this three-year study has shed significant light on *the urgent need to continue APS and vulnerable adult maltreatment research and to address the ability of APS programs to contribute to the research needs within the field.* For example, the lack of research-readiness, specifically the significant inability of many APS programs to be able to provide aggregated data needs to be addressed. (NOTE: Significant improvements have occurred in the past several years in APS state program data systems due to the NAMRS and ACL APS State Enhancement Grants). Similarly, the significant need for increased research regarding APS case assessment tools has been revealed via the tools research conducted during this project.

II. Lessons learned

A. Lessons learned from the literature review project component

1. The existing self-neglect research is inadequate.

The fact that only 73 bona fide research projects were conducted in the country over a 20-year period reveals the scant nature of self-neglect research, despite the fact that it is the most frequently reported and substantiated allegation to APS nationally. We also realized that the majority of the research findings came from just three populations. Moreover, the majority of the study designs were observational (i.e. cross-sectional or descriptive in nature) and therefore lacked temporal precedence needed to assess the relational nature of self-neglect to many of the identified social determinants and outcomes such as physical function, cognition and mental and physical health findings. The many other deficiencies also precluded drawing useful information for a meta-analysis.

2. Available research regarding self-neglect by younger vulnerable adults is particularly scant.

The self-neglect research that has occurred has focused almost exclusively on elders. Of the 73 research articles reviewed, only 8 addressed self-neglect of adults of all ages, 89% addressed only older adults.

3. A variety of conditions have been found to be associated with elder self-neglect.

These include: Social isolation; depression; economic deprivation; functional, physical, and cognitive impairment; poor health and untreated pain; executive dysfunction; substance abuse; unsanitary living conditions; and hoarding.

4. The outcomes of self-neglect are extremely harmful.

The outcomes associated with self-neglect include elevated risk of functional and cognitive decline, illness, hospitalization and readmission, hospice and nursing home placement,

and mortality for those affected. Those who self-neglect are also at elevated risk of abuse perpetrated by others.

5. Summary conclusions from the literature review include the following:

The published self-neglect research includes analyses of data subsets from large population studies (CHAP and PINE); from research conducted in collaboration with APS (CREST), and from secondary data using APS sources (New Haven EPESE study). Studies conducted by geriatricians often use subjects age 65 and older, and their primary focus is medical. These limit generalizability to a subset of the APS client population, which in most states includes adults 18 years and older. Theories of causation of adult self-neglect include physiological factors such as frontal lobe disorder, resulting in executive function impairment; and medical conditions that precipitate depression. Endogenous factors may include diabetes, major psychiatric disorder, personality disorder, and Obsessive Compulsive Disorder. Exogenous factors may include lack of support network, lack of resources and inadequate housing, and lack of access to food, water, and utilities. Studies note differences in those who self-neglect based on race and gender. Refusal to accept services when offered is a common theme. Self-neglecting behavior may be influenced by substance abuse, related to pain and self-medication with alcohol and prescription drugs. Self-neglect ranges along a continuum of seriousness, which at some point may trigger an APS report and investigation, depending on state and local APS screening and assessment differences. Intervention options are affected by willingness of self-neglecting clients to accept services and the availability of needed services.

B. Lessons learned from the 2017 SNAPS survey (detailed in Appendix D)

1. Many state APS programs experienced significant challenges in providing aggregate data regarding abuse reports and cases handled in FY '16. It was challenging for many, and impossible for some, state APS programs to provide aggregate data to our 2017 SNAPS survey in response to questions on page 4, section “C. FY '16 Report and Case Information.”

The patterns and proportions of missing data varied across questions. Regarding data specifically addressing APS reports received, screened in, validated, and provided intervention the range of missing data was 8 (Total number of APS reports received) to 34 (Number of validated self-neglect clients provided intervention). Importantly, half of the programs did not provide the number of APS reports alleging self-neglect. Almost all programs provided the number of reports screened-in while 15 did not report this number for self-neglect. A similar level of missing data occurred for the number of self-neglect referrals substantiated.

ACL awarded the first state APS program enhancement grants in September 2015. Since that time and with these grants, a number of state APS programs have enhanced their data systems to better report aggregate report and case information consistent with NAMRS. The improvements to APS programs, made possible by these awards, likely have resulted in improved capability of APS programs to effectively contribute to wide-ranging research projects, including those such as our NAPSA Self-Neglect Project. We hypothesize that if we were to secure funding to redo our SNAPS nationwide APS survey, the states would over-all be better able to provide these data.

2. In a small portion of the U.S., APS services were not available to younger vulnerable adults, that is, adults age 18 - 59 experiencing disabilities. Four states (Connecticut,

Nevada, Ohio, Rhode Island) provided Protective Services to older adults, but not to younger especially vulnerable experiencing disabilities. As noted in the ACL Voluntary Guidelines for State APS Programs, “Adult maltreatment is a significant public health and human rights problem.” (ACL Guidelines, p.2). Furthermore, “...ACL seeks to help ensure that older adults and adults with disabilities are afforded similar protections and service delivery, regardless of which state or jurisdiction they are in. ... a consistent approach for APS systems displays the value this nation places on its older adults and adults with disabilities...” (ACL Guidelines, p.1). Our SNAPS finding regarding this inequity in APS services paved the way for efforts to bring protective services to those not served. As an example, the Project Director collaborated with the state of Nevada to apply for and receive a 2018 ACL APS State Enhancement Grant to help them expand their APS services to younger vulnerable adults. This exciting and very much needed project is now successfully underway. The state of Nevada received legislative authority to receive and respond to reports of abuse and neglect of younger vulnerable adults and the new Nevada APS (having expanded from an EPS Elder Protective Services) opened its doors on July 1 of this year and is now effectively serving younger vulnerable adult victims. So, in three of the four states that lacked APS services for younger vulnerable adults in 2017, younger vulnerable adults continue to be ineligible for APS services. This constitutes a significant unmet service gap.

3. Not all state APS programs provide services for vulnerable adults who are self-neglecting. As described earlier, only 49 of the 53 state APS programs indicated on SNAPS that they investigate reports of alleged self-neglect. This is one example, among many, of the differences among APS programs across the nation. Given the harmful outcomes of self-neglect

documented by research, it seems prudent that the remaining three states that do not respond to self-neglect of vulnerable adults follow the state of Illinois in seeking legislative approval to expand their services to this vulnerable population.

4. The variation in legal definitions and protocols across the U.S. makes measuring the frequency and outcomes of self-neglect investigations by APS very difficult. For example, one state specifically excludes inadequate resources (typically due to poverty), while two states explicitly include that condition. Some states include chosen acts while others define the victim as physically and/or mentally unable to provide adequate resources for safety.

Hoarding is included in the “action or inaction” aspects of some definitions, a unique complex problem often identified with mental illness and chosen lifestyle. Uniformity of legal definitions is unlikely to be readily achieved due to the ethical dilemmas encountered when self-determination is a high value for those with comprehension and appreciation of their circumstances. A discussion of these definitions and policies is contained in **Appendix J**.

5. APS programs have been insufficiently involved in research addressing self-neglect. SNAPS revealed that prior to this NAPSA project, only four (8%) state APS programs had collaborated in self-neglect research. This finding suggests the value of the current project in which participation was garnered from all 53 state APS programs in contributing to self-neglect research and the resulting practice knowledge.

6. Many, but far from all, APS programs collaborate with tribes. The extent and involvement of APS/tribal collaborations have been much less-well explored and reported than CPS/tribal collaborations. Our SNAPS survey revealed that 40% (N = 21) of the 53 state APS programs collaborate, on some level, with American Indian or Alaska Native (AIAN) tribes in

responding to cases of self-neglect. SNAPS elicited information regarding the specifics of these APS/tribal collaborations (detailed in **Appendix K. Table of State APS-Tribal Collaboration**). This information laid a foundation for the site visit made to the St. Regis Mohawk Tribe APS program that functions as part of the NYS APS program as well as the “Self-Neglect and Tribal Elders: Collaborations with APS” presentation at the 2017 NAPSA Conference. In summary: All of 53 statewide APS programs submitted SNAPS. Among them, 21 (40%) collaborate with AIAN tribes in responding to cases of self-neglect. Significant Finding: The systematic literature review conducted by the Self-Neglect Project reveals that no research has been published in the U.S, over the past 20 years regarding self-neglect among American Indians or Alaska Natives or APS response to AIAN self-neglect cases. **Conclusion: Over 1/3 of statewide APS programs collaborate with tribes, however, there is no evidence that APS-tribal collaborations have been systematically explored, documented, or reported.**

7. Another lesson learned with surprise and concern is the wide range of assessment tools in use within APS programs to screen for mental capacity. It appears that many are used without any significant verification of the quality of the tool regarding validity and reliability. In addition, APS staff may be using these tools without sufficient training. This critical need to educate and direct staff to appropriate tools can and should be remedied. In addition, tools to measure the presence and degree of self-neglect are available but not in common use by APS staff across the country. This additional gap in training must be addressed as well (further described in **Appendix H. 2019 Tools Findings**).

8. Innovative APS self-neglect practices and collaborations are limited and need to expand. As described previously, about one-quarter of the state APS programs responded

affirmatively to SNAPS question E1 (page 6, Appendix D): “Do you use one or more innovative practices to prevent or respond to self-neglect cases?” Analysis of the practices reported as innovative revealed that some were quite vague or, while innovative for the involved program, have been standard in many locales for years. We did select and explore innovative self-neglect practices in four jurisdictions: Florida, Texas, Washington, DC, and the St. Regis Mohawk Tribe collaboration with New York State APS. Several of these are described in Appendix F.

9. Relevant Descriptive Statistics and Bivariate Associations - Given the availability of the data and the missing patterns previously discussed, the applied statistical approach was limited to simple descriptive statistics and bivariate correlations. *We found that approximately 80% of self-neglect cases are screened in for investigation compared to 51% of abuse cases with respective substantiation rates of 43% and 26%. Only 7 states reported having self-neglect subject matter experts (SME) with 3 states reporting that their SMEs only train and consult and do not work cases. The availability of self-neglect SME was not associated with overall reported 2016 budget and did not result in more self-neglect cases being screened in, substantiated, provided intervention or opened longer.*

The number of full time employees (FTEs) was positively correlated with the total number of self-neglect reports screened in, substantiated and provided intervention. Similar findings were confirmed for non-self-neglect cases. These findings are considered artifacts of state population and budget size rather than program procedural variations. We based our assumption on the following findings: 1) larger budgets were associated with states that have larger populations, 2) states with larger populations had higher numbers of cases reported for both elder mistreatment and self-neglect, 3) larger budgets were associated with higher number of FTE’s, 4) higher

budgets were associated with *higher numbers* of cases screened in, but 5) higher budgets *were not correlated with the percent* of self-neglect cases screened in, substantiated, or provided intervention. In essence, *we concluded that states, despite budget size, appear to be practicing in similar manners.*

We also found that budget was not related to having specialized self-neglect training, SMEs or practices for tracking self-neglect outcomes. However, 37% of programs track repeat self-neglect cases. It remains unknown how having higher budgets and more staff affects staff to case ratio since there was a positive correlation between FTE's and length of time a case is open.

C. Lessons learned from the exploration of innovative APS program practices and collaborations

1. Florida put an innovation in place in attempt to successfully engage self-neglecters who had been repeatedly reported to APS in service-acceptance. This innovation is described in Appendix F. This was a very well-motivated innovation that did show promise in helping to reduce repeat self-neglect reports. Unfortunately, staff overwork and other practical barriers resulted in the practice being discontinued.

2. An innovative culturally-relevant collaboration exists in northern New York State between the APS program and the St. Regis Mohawk Tribe. This is also described in Appendix F.

D. Lessons learned from the 2019 Tools Survey

The expanded tools survey confirmed suspicions of the field. The majority of APS programs do not utilize or employ psychometrically tested (i.e. reliable and validated) assessments of self-neglect. In fact, some programs are using clinical assessments designed to

screen for geriatric syndromes such as depression, executive dysfunction and memory impairments. These assessments require trained administration and interpretation begging the question of their appropriate use by APS caseworkers for determining the most appropriate interventions and in some instances, restrictions for self-neglect and other allegations. The vast majority of the assessments were used across all cases and few were specified solely for self-neglect. Of interest and concern, no APS programs were using any of the available psychometrically tested self-neglect assessment tools. Details regarding tools findings are provided in **Appendix H**.

4. What will happen to the project after this grant has ended?

Will project activities be sustained? Will project activities be replicated? If the project will be sustained or replicated what other funding sources will allow this to occur? Please note your significant partners in this project and if/how you will continue to work on this activity.

Researchers Ramsey-Klawnsnik and Burnett would like to replicate the full SNAPS survey and will seek federal funds to do so. An updated national survey of APS program policies, procedures, etc., among other things, would provide another window for assessing the effectiveness of the ACL APS State Enhancement Grants that have been funded since 2016. Ramsey-Klawnsnik and Burnett also find it prudent to include questions to APS programs detailing specifically how the state enhancement grants have helped them with reporting and research readiness such as SNAPS questionnaires. These grants have improved the data systems in multiple APS state programs and, we hypothesize, done much to enhance the research-readiness of APS state programs. The researchers also plan to apply for and hope to obtain federal funding to continue and to expand our APS case/client assessment tools research. This

ACL-funded self-neglect project has resulted in foundational knowledge upon which to build and go forward with this important and needed social science and humanitarian research. At the present time, Ramsey-Klawnsnik is consulting with New Editions on their work on identifying valid/reliable vulnerable adult abuse screening tools. This is one way in which the work of the current NAPSA project is being continued and contributing to further research.

Significant Project Partners:

Holly Ramsey-Klawnsnik, Ph.D., is the Director of Research, NAPSA, and served as the Project Director. She is a Sociologist; Licensed Marriage & Family Therapist; and Licensed, Certified Social Worker who has provided clinical, teaching, staff development training, consultation, and research services in the social work and mental health fields since 1970. She has conducted multiple research projects regarding child and vulnerable adult maltreatment and professional response to maltreatment since the mid-1980's using child and adult protective services as well as clinical and court data. She has published widely regarding interpersonal violence, victimization, trauma, and professional and public response to these social problems.

Jason Burnett, Ph.D., is an associate professor with the UTHealth McGovern Medical School, Division of Geriatric and Palliative Medicine (Primary) and School of Public Health, Department of Health Promotion and Behavioral Sciences (Secondary). Dr. Burnett serves as the Co-Director of the Texas Elder Abuse and Mistreatment Institute (TEAM) and the Director of the Research and Program Evaluation Division of TEAM. He has been studying self-neglect since 2005 and has expertise in public health intervention development, research design, intervention mapping, program evaluation and quantitative statistics, and has conducted multiple self-neglect research projects. Dr. Burnett served as Project Statistician and Self-Neglect Research & Tools Expert.

He collaborated with the Project Director throughout the project, particularly regarding to the nationwide 2017 SNAPS research and the 2019 APS case assessment tools research.

Patricia Brownell, PhD, is Associate Professor Emerita of Social Service at Fordham University and Emerita Scholar, Ravazzin Center on Aging, Past-President of NCPEA, consultant to the United Nations Department of Economic and Social Affairs for an Expert Group Meeting on Neglect, Abuse and Violence Against Older Women, Past President of the State Society on Aging of New York and is a John A. Hartford Geriatric Social Work Faculty Scholar. Dr. Brownell assumed primary responsibility for the self-neglect literature search and report and coordinated the participation of NCPEA experts in the Self-Neglect Mini-Think Tank.

Carol Dayton, MSW, LISW, ACSW, is a private consultant and retired APS practitioner. Her work in the field of aging began with a joint appointment as a caseworker and researcher at the Benjamin Rose Institute. Her interest in the link between research and practice has continued. From 1993 to 2005, Ms. Dayton was Chief of Adult Protective Services at the Cuyahoga County (Greater Cleveland, Ohio) Department of Senior and Adult Services. Since then she has worked as an independent consultant, participating in and leading national, statewide and local boards, commissions, coalitions and roundtables. From 2007 to the present, Ms. Dayton has served as the Co-Chairperson of the joint Research Committee of NAPSA and NCPEA. In 2018 she was awarded the NAPSA Rosalie S. Wolf Award for her leadership in creating and developing the Research Committee. Her publications include a focus on self neglect. She is a member of the NAPSA Board of Directors and throughout this project has served as the Board representative to the work .

5. Over the entire project period, what were the key publications and communications activities? How were they disseminated or communicated? Products and communications activities may include articles, issue briefs, fact sheets, newsletters, survey instruments, sponsored conferences and workshops, websites, audiovisuals, and other informational resources.

Key publications and communications activities:

1. In conjunction with the 2017 NAPSAs Annual Conference in Milwaukee, we conducted the project Mini-Think Tank. All of our project components were discussed with invited elder abuse, self-neglect, and APS experts at the “**Self-Neglect Mini-Think Tank**” conducted on August 28, from 9 AM – Noon just prior to the start of the NAPSAs conference. At that time, our findings were incomplete and under analysis. The process of the each project component was discussed along with emerging trends and plans for project completion.
2. As part of our project disseminate plan and to promote national understanding of the complexities of self-neglect, we hosted a special **7.5 hour Self-Neglect Track** at the 2017 annual NAPSAs conference. The track was well-attended and the participant evaluations were positive. Those who attended the entire track were awarded a certificate of special training in self-neglect which proved to be of interest to many.
3. “**The Cutting Edge in Self-Neglect: ACL Innovation Grants to Understand Self-Neglect**” was presented in August 2017 at the Annual NAPSAs Conference by Ramsey-Klawnsnik; Aiesha Gurley, ACL; Stephanie Bergen, Rush University Medical Center; and Dr. Farida Ejaz, Benjamin Rose Institute on Aging.
4. “**The NAPSAs Self-Neglect Project: Policy, Practice & Research Realities & Needs,**” was

presented in August 2017 at the Annual NAPSA Conference by project team members.

5. **“Self-Neglect and Tribal Elders: Collaborations with APS”** was presented by members of the project team along with Kristin Post, Lead Caseworker of the Saint Regis Mohawk Tribe Adult Protection. This presentation emanated from the project’s exploration of APS collaborations with AIAN tribes and was part of the August 2017 Annual NAPSA Conference.
6. On November 2, 2017 Ramsey-Klawnsnik presented, **“Role & Relationship of Isolation to Self-Neglect”** at the New York State Adult Abuse Conference. The NAPSA self-neglect project was discussed in relation to cutting edge research on self-neglect.
7. In February 2018 Ramsey-Klawnsnik prepared the **“Systematic Literature Review of Self-Neglect Research - Preliminary Brief”** (Appendix C) regarding journals that published the studies included in our literature search. With the approval of Project Officer Gurley, it was released to the NAPSA/NCPEA Research Committee to inform their efforts to identify journals publishing works helpful to APS practice.
8. On March 26, 2018 Ramsey-Klawnsnik and Andrew Capehart presented on our project at the American Society on Aging conference in San Francisco. This panel presentation was moderated by Mary Twomey, ACL Program Officer and co-presented with those conducting the Benjamin Rose ACL self-neglect project.
9. On May 17, 2018 Ramsey-Klawnsnik presented a day-long seminar entitled, **“Understanding & Responding to Self-Neglect”** in North Carolina for an interdisciplinary audience. The NAPSA self-neglect project was discussed along with clinical and practice findings and issues. The North Carolina APS program collaborated by sending staff to both participate

and deliver a 45 minute talk on APS response to self-neglect and APS in that state.

10. On August 28, 2018 **“Where New Knowledge is Taking Us: ACL Elder Justice Self-Neglect Innovation Grants”** was presented at the Annual NAPSA Conference by Hillary Dalin of ACL, Ramsey-Klawnsnik, and Farida Ejaz, PhD of the Benjamin Rose Institute on Aging.
11. On August 29, 2018 **“Preliminary Findings from NAPSA Self-Neglect National APS Survey Research”** was presented by Ramsey-Klawnsnik and Jason Burnett, Ph.D. At the Annual NAPSA Conference.
12. On April 16, 2019 Ramsey-Klawnsnik presented project work and preliminary findings at the American Society on Aging Annual Conference in New Orleans. Project Officer, Aiesha Parry and Dr. Farida Ejaz of the Benjamin Rose Institute co-presented, **“Self-Neglect: An Update on Elder Justice Innovation Grants Funded by Administration for Community Living.”**
13. Ramsey-Klawnsnik presented **“Confronting Self-Neglect: An Elder Maltreatment Sticky Wicket”** for the American Society on Aging in observance of World Elder Abuse Awareness Day, June 15, 2019. This webinar defined self-neglect and described commonly-involved behaviors. Practice and research findings were presented, including etiological and contributing factors, the known extent of self-neglect and its associated outcomes, impact on those who self-neglect and on others, and ethical issues and dilemmas. We discussed prevention and intervention and considered broad sociological forces and factors that profoundly affect the ability of older adults to provide adequate self-care. The NAPSA self-neglect project was described.

14. Ramsey-Klawnsnik prepared a blog for the APS TARC entitled, “**Self-Neglect Knowledge, Policy, Practice & Research: Realities & Needs The NAPSA ACL Elder Justice-Funded Project**” which was published on the ACL website on July 2, 2019.
15. On August 20, 2019, Ramsey-Klawnsnik, Jason Burnett, and Stephanie Whittier Eliason presented, “**What Have We Learned: Emerging Findings from the NAPSA Self-Neglect Project**” at the Annual NAPSA Conference.

Summary and Recommendations

This project has been a federally-funded, multi-pronged national endeavor to apply the tools of social science to illuminate current methods of identifying, assessing, and intervening with dangerously self-neglecting vulnerable adults, a specific and specialized area of APS practice. As demonstrated by the project, vulnerable adult self-neglect is understudied and highly dangerous. This project has brought together the skills, experiences, and knowledge base of multi-disciplinary professionals (detailed in **Appendices J. Tools Panel Bios and L. Staff and Consultants - Project Year-One**) to collaborate in this first-ever national self-neglect data-gathering and analysis. The macro-level analysis has relied upon a confluence of mixed methodologies, as the best of social science does.

APS practice over-all, as well as the subspecialty of self-neglect practice, has been under-researched. Given the significant harmful consequences of not only adult self-neglect, but all forms of vulnerable adult maltreatment addressed by APS, vastly expanded APS research is needed. Expanded research can inform APS and related efforts to curb violence, victimization, and costly and dangerous self-neglect among a highly vulnerable portion of the U.S. population -

adults who are of advanced age or have disabilities that prevent effective self-care, self-protection, and self-advocacy.

Quality social science research is a marriage of researchers and practitioners. Practice-informed research, and research-informed practice, cannot occur without this. This project's findings and recommendations are the result of such collaboration. They could not have been accomplished without the significant contributions of APS programs and practitioners, nor without the highly specialized skills of the academic researchers. The Project Director and Project Team are most appreciative of this extraordinary opportunity to conduct this needed study, and most grateful to our federal government and the U.S. Department of Health and Human Services, Administration for Community Living, for funding and supporting the work.

We especially acknowledge the following contributors:

- ACL Project Officer Aiesha Gurley Parry and the full ACL staff
- All State and Territory APS Programs and Their Program Administrators
- Special Thanks to Florida, Texas, Washington, DC, and NYS APS Programs
- The St. Regis Mohawk Tribal APS Program of NYS
- The APS TARC
- The NAPSA Board of Directors and Regional Representatives
- The NAPSA Project Team and Consultants.

Project Limitations:

- Not all state APS programs had the data needed to fully contribute.
- There is much more work to do to comprehensively study self-neglect and APS response.
- We had limited project staff, timeframe, and budget.

Project Strengths:

- This has been the first nationwide study of self-neglect and APS response.
- Social science methods have been rigorously applied throughout.
- An interdisciplinary team of researchers and practitioners have contributed.
- There has been broad and national APS input.
- We achieved a 100% response to the national APS survey from state programs.
- We have achieved a confluence of findings from mixed methods.
- We have tested associations with the available statistical data.
- The project reveals the continued need for self-neglect and APS research.
- The project also provides data that informs areas needing continued attention.
- Our confluence of findings reveals an urgent need for expanded APS research.

Major findings:

Self-neglect is the most frequently reported allegation to APS programs across the nation. It is a profoundly serious and harmful set of behaviors in which adults, often due to functional or cognitive limitations, health problems, untreated pain, insufficient resources, mental illness, or substance abuse fail to provide sufficiently for their basic human needs. People who self-neglect are at high risk of illness, hospitalization and readmission, hospice and nursing home use, and early mortality, as well as abuse by others. Factors such as fear, social isolation, and depression often inhibit those suffering from self-neglect from accepting services to improve their quality of life and reduce their suffering. Of interest, one study revealed that among those who did accept APS services for self-neglect, 75% reported satisfaction with the overall services received.

Despite the high APS caseloads for this problem and the profoundly harmful outcomes, woefully little scientific research has occurred to better understand the problem, its etiology, and

effective treatment approaches. Only 73 scholarly works on the subject were published over the twenty-year time period of our analysis.

Another factor limited the effective study of self-neglect is the lack of research-readiness found among APS programs at the time of our 2017 nationwide survey. While we learned a great deal regarding APS policies and procedures in place to address self-neglect, many programs had insufficient data systems able to provide clear information regarding the number of either total case reports for all allegations or specific self-neglect reports that they had received, investigated, substantiated, provided intervention, or were re-reported.

A third concerning finding involves case and client assessment tools in use by APS programs. It is apparent that insufficient APS-specific, tested case assessment tools exist to enable APS caseworkers to reliably and with validity assess the extent and types of problems experienced by their clients. Without sufficient assessment tools, workers are handicapped in their efforts to construct and implement effective intervention plans, and further handicapped in measuring and documenting casework success.

Project Recommendations:

- 1) Increased funding is needed for both self-neglect and APS research.
- 2) Organizations concerned with the welfare of vulnerable adults, such as NAPSA, ACL and other federal agencies, must prioritize funding, supporting, and conducting self-neglect and APS research.
- 3) Data systems for APS programs must be properly funded, created, and maintained to promote both effective service to clients and scientific research.

- 4) Collaborations between researchers and APS practitioners must be supported, funded, and encouraged.
- 5) Significant effort must be put into creating and testing APS-specific case/client assessment tools and training and supervising APS staff in the appropriate use and limitations of these tools.

Appendix A

Master Bibliography for Adult Self-Neglect Literature Review

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Appendix B.
NAPSA Self-Neglect Project
Systematic Literature Review
Tables of Key Findings

Table A. Studies targeting the understanding of specific Self-neglect Behaviors

| Author, Year | Study Purpose | Design | Primary Findings |
|------------------------|---|---|---|
| Abada et al., 2017 | Determine whether medication regimen complexity predicts medication adherence levels among self-neglecters | Cross-sectional study (N=31 self-neglecters) | Increased medication regimen complexity was significantly associated with lower adherence adjusted for executive function. |
| Burnett et al., 2014 | Determine if there are subtypes of SN behaviors with different risk factors that can be targeted using medical and social interventions | Aggregated Cohort Study (N = 5,686 self-neglect cases) | Four subtypes found and included physical and medical neglect only (50%) environmental neglect only (22%), global neglect (21%), & financial neglect only (9%). Environmental neglect associated with impaired ADLs. |
| Culberson et al., 2011 | Describe prescription medication use behaviors in self-neglect | Case-control study (n=50 self-neglecters) and (n=50 matched controls) | SN elders use fewer prescription drugs than controls but have higher benzodiazepine use and similar prevalence of opioid analgesics, non-benzodiazepine sleep aids, and muscle relaxant use. |
| Arluke et al., 2007 | Assess association between ADL impairment and animal hoarding including impact on health and safety of household members | Cross-sectional study (N=71) animal hoarding professionals | Most hoarders female; ½+ had others in home. Those living alone had more ADL impairment, non-working utilities, unsanitary conditions. Extreme filth, human & animal waste, contaminated atmosphere, concern for vulnerable persons cohabitating. |

Table B. Cognition, Capacity and Mental Health

| Author, Year | Study Purpose | Design | Primary Findings |
|----------------------------|--|--|---|
| Hansen et al., 2016 | Identify factors correlated with depression in self-neglect | Cross-sectional study (N=96) self-neglecters | Self-reported pain, past history of alcohol abuse and lower self-rated pain associated with higher odds of depression. |
| Aamodt et al., 2015 | Identify distinguishing demographic and cognitive characteristics between APS clients living in squalor & not living in squalor receiving capacity assessments | Retrospective Case Control study (N = 50 squalor & 189 non-squalor). | Both groups has impaired executive function, but No significant differences in executive function or visuospatial ability. Squalor-dwellers performed better on memory & general cognition. |
| Dong et al., 2010 | Examine longitudinal association between cognitive decline and risk of elder SN | Prospective Cohort study (N=1,017, Self-neglect = XXX) | Decline in executive function associated with greater risk of reported and confirmed SN. |
| Schillerstrom et al., 2009 | Assess differences in executive function between APS clients referred for capacity consultations and 58 controls | Cross-sectional study (n= 63 APS clients, n=58 controls) | APS clients performed worse, but general cognitive abilities did not distinguish between groups. Self-neglecters scored worse than other APS clients did. Squalor unrelated to differential poorer performance. |
| Abrams et al., 2002 | Determine if depressive symptoms and cognitive impairment predict SN | Cross-sectional study (N=2,812, n= 92 Self-neglecters) | Depressive symptoms and cognitive impairment significant predictors of SN alone and after adjusting for SES and medical variables. |
| Dyer et al., 2000 | Assess association of depression and dementia clinical diagnoses between APS clients and matched controls | Cross-sectional study (n=47 APS clients of which 37 were Self-Neglect and n=97 matched controls) | Both depression and dementia were more common in APS clients and self-neglecting patients The two groups did not differ in other parameters of the geriatric assessment (e.g. ADL's, other medical diagnoses) |

Table C. Self-Neglect Tools

| Author, Year | Study Purpose | Design | Primary Findings |
|----------------------|--|--|--|
| Abrams et al., 2018 | Estimate internal consistency reliability and inter-rater agreement on a novel scale for classifying SN | Cross-Sectional Study (N=71) cases of self-neglect | ICC reliability was good with SN participant responses having the lowest reliability (0.68-0.69) and observer ratings the highest (0.76-0.77). |
| Burnett et al., 2014 | Estimate validity, reliability and measurement invariance of a SN & EA assessment used by Adult Protective Services | Aggregated Cohort Study (N=7,580) APS validated cases of Elder Abuse and Self-Neglect | The assessment had high reliability, validity and was measurement invariant across race/ethnicity and gender. |
| Iris et al., 2014 | Estimate the psychometric properties of the Elder Self-Neglect Assessment (ESNA). | Cross-Sectional Study (N=215) APS cases of Self-Neglect | ESNA is a reliable assessment tool of SN environmental and behavioral characteristics and improves the identification of SN and SN severity. |
| Iris et al., 2010 | Create a conceptual map of SN | Cross-Sectional Study (N=20) senior services professionals and researchers | A 7-cluster conceptual map identified with highest importance ratings being physical living conditions and mental health. All clusters were highly interrelated. |
| Burnett et al., 2009 | Evaluate convergent validity of KELS with tests of common social determinants of self-neglect. | Cross-Sectional study of 100 APS validated cases of self-neglect and 100 matched controls | KELS performance had the highest convergence with executive function measures and less with general cognitive and physical abilities and no significant convergence with depression. |
| Kelly et al., 2008 | Scale development for correctly classifying self-neglecters from non-self-neglecters on APS and clinical geriatric medicine caseloads. | Expert panel review and classification of 30 cases and 30 controls based on scale findings | Self-neglect Severity Scale distinguished self-neglect from non-self-neglect and had adequate reliability and correlation with case status, although sensitivity and specificity fell below the conventional acceptable range. |

| | | | |
|-------------------|---|---|---|
| Dyer et al., 2006 | Describe development of the Self-Neglect Severity Scale (SSS) | Descriptive study of scale developed by expert panel | SSS utilizes observer ratings, interview responses, and assesses subjects' physical and environmental domains. Also assesses functional status related to health and safety issues. |
| Naik et al., 2006 | Develop a screening tool for APS caseworkers to identify decision-making capacity concerns presented in self-neglect. | Cross-Sectional Study of 91 APS validated cases of self-neglect and 91 matched controls | Cognitive impairment was not more common among SN cases compared to matched controls. Findings did not support validity of COMP screen for decision-making capacity in setting of SN. |

Table D. General Self-neglect Studies that did not fit the other categories, but add new information.

| Author, Year | Study Purpose | Design | Primary Findings |
|----------------------------|--|---|---|
| Booker et al., 2017 | Assess self-neglect client satisfaction with APS services | Cross-sectional study of N=77 APS validated cases of self-neglect | 75% reported satisfaction with the overall services citing responsiveness to their needs and addressing their problems. > 80% would refer a friend and were at least satisfied with the amount of help received. Extent to which needs were met was unsatisfactory. |
| Ernst et al., 2012 | Compare differences between nurse/social worker team and lone social worker in case disposition, risk reduction, recidivism, and cost effectiveness. | Cross-sectional study (N = 896) cases | No significant differences in confirming self-neglect or in recidivism; Lone SW more likely to confirm other forms of abuse. Greater risk reduction in county with SW/RN team for all risks except exploitation. Enhanced team not cost effective. |
| San Filippino et al., 2007 | Investigate differences in perception of SN behaviors among aged and cultural groups | Cross-sectional study (N = 494) | Age and cultural influence perceptions of what constitutes self-neglect behavior. |

| | | | |
|-----------------------|---|--|---|
| Dyer et al., 2005 | Develop a definition of elder neglect. | Cross-sectional study (N=XXX) APS case workers | SN generalized as inability or unwillingness to care for oneself. 58% felt SN was an inability to care for oneself, 8% felt it was unwillingness to care for self, 36% felt it was both |
| Reynolds et al., 2004 | Assess frequency and trends in cases reported to APS hotline (n=146,913) and examine trends in types of abuse reported 1993-1998. | Descriptive study (N=146,913) | 25% of cases were for self-neglect (less common than neglect & physical abuse). Self-neglect, physical abuse, and financial exploitation reports increased over the study period. |

Appendix C.

Systematic Literature Review of Self-Neglect Research Journals that Published Included Articles

Project Overview: This project entails: 1) A systematic literature review of self-neglect (SN) research published in the U.S. over 20 years; 2) 2017 National survey research regarding Adult Protective Services (APS) program SN policies, procedures, and FY '16 report and case numbers; 3) An exploration of innovative APS practices and collaborations to address SN; and 4) An updated 2019 mini-survey of case/client assessment tools employed by APS programs.

This brief lists the peer-reviewed journals that published research included in our review analysis. Out of over 3,000 potentially relevant articles initially identified, 73 were analyzed after application of search criteria.

The following journals (J) published multiple relevant SN articles included in our analysis:

- J of Elder Abuse & Neglect – 23 publications
- J of the American Geriatrics Society - 8
- The Gerontologist – 5
- J of Aging & Health - 4
- J of Gerontological Social Work – 3
- Aging Mental Health - 2
- American J of Geriatric Psychiatry – 2
- Health & Social Work – 2
- J of Applied Gerontology – 2
- J of the American Medical Association – 2

The following journals published one included SN article:

- American J of Emergency Medicine
- American J of Psychiatry
- American J of Public Health
- Archives of Gerontology and Geriatrics
- Archives of Internal Medicine
- Archives of Physical Medicine and Rehabilitation
- Behaviour Research & Therapy
- Clinical Gerontologist
- Drugs & Aging
- Family and Consumer Sciences Research J

Geriatrics and Gerontology International
Gerontology
Health & Social Work
J of Addictions Nursing
J of American Academy of Nurse Practitioners
J of American Geriatrics Society
J of Applied Gerontology
J of Gerontology: Biological & Medical Sciences
J of Nutrition
J of the Society for Social Work and Research

Appendix D

Self-Neglect Adult Protective Services (SNAPS) Program Assessment

Purpose of this Questionnaire

NAPSA is undertaking an Elder Justice ACL-funded project entitled, “**Self-Neglect Knowledge, Policy, Practice & Research: Realities & Needs.**” This project addresses self-neglect among adults with disabilities age 18 and over. Our goal is to contribute to the self-neglect knowledge base and inform research, policy and practice. Primary objectives include enhancing existing knowledge regarding responses of APS and other programs to self-neglect and promoting evidence-based APS practice. Key steps include a systematic examination and analysis of APS self-neglect policies and practices nationwide and an exploration of APS-community collaborations to respond to self-neglect. This cannot be accomplished without APS Program input.

All statewide APS Program Administrators are asked to please complete this questionnaire to provide program information. The results of all project components, including findings from this **Self-Neglect Adult Protective Services (SNAPS)** survey, will be analyzed, distributed, and provided to you.

Instructions

This form is designed to record APS information. We request that one be completed for each statewide or territorial program. APS Administrators are asked to **please reply using FY’16 data. If a question does Not Apply to your program, please reply "NA." If a question requests data that your program does not track or tabulate, please reply “Not Tracked.” This survey is designed to enable respondents to save their work on incomplete questionnaires and complete at a later time if needed. Thank you very much!**

Please direct questions to:

- Dr. Holly Ramsey-Klawnsnik, NAPSA Self-Neglect Project Director
holly.ramsey-klawnsnik@napsa-now.org 202-448-8904
- Mr. Andrew Capehart, NAPSA Assistant Director
andrew.capehart@napsa-now.org 202-333-5622

Completed by _____ Date _____

Position _____

Email _____ Phone _____

A. PROGRAM INFORMATION

1. Name of US state or territory
2. Name of APS Program
3. Agency and department/division within which APS Program is located
4. What are the dates of your fiscal year?
 - a. July 1 – June 30
 - b. October 1 – September 30
 - c. Other, please specify
5. Total APS program budget for the 2016 fiscal year
6. Sources of funds (please check all that apply and provide % of funds from each source)
 - a. Social Services Block Grant (SSBG)
 - b. State General Revenue/Funds
 - c. Older Americans Act (OAA) Funds
 - d. Victims of Crime Act (VOCA) Funds
 - e. Local property tax or mills
 - e. Other (please describe)
7. APS program (indicate all that apply):
 - a. Is state administered and operated;
 - b. Is state-supervised and county administered;
 - c. Is county-administered;
 - d. The state contracts with local agencies to provide APS services
 - e. Other (please specify)
8. Please describe the population your program serves, indicating if you serve both younger adults with disabilities and older adults.
9. Number of FTEs APS administrative/management staff

10. Number of FTEs APS supervisors
11. Number of FTEs APS caseworkers including investigators
12. Number of FTEs APS trainers
13. Number of FTE APS nurses
14. Are reports of alleged self-neglect (SN) investigated by your program?
 - a. Yes
 - b. No (If no, are those calling to report SN given suggestions for obtaining assistance for alleged self-neglectors?)
15. If reports of alleged SN are investigated, how is SN defined in the program?
16. What is the source of this definition (e.g. statute, policy, etc.)?
17. Does your state law identify mandated reporters for SN?
18. Does the program provide staff with specialized SN training?
 - a. Yes (please describe curriculum and length and frequency of training)
 - b. No
19. Do you have staff identified as SN specialists or subject matter experts?
 - a. Yes (please describe and provide number of)
 - b. No
20. Does your state APS law allow program staff to request Court Orders to gain entry to the dwelling of alleged self-neglecting persons who refuse access to assess their condition?
21. Does your state APS law allow program staff to request Court Orders to remove self-neglecting persons from danger?
22. Do you track outcome data on SN cases that receive intervention?
 - a. Yes
 - b. No
23. Do you track data on SN cases repeatedly reported to your program?
24. Do you have specific protocol for responding to repeatedly reported SN cases?
 - a. Yes (please describe)
 - b. No

25. Within your protocol(s) to protect worker safety, do you have specific sections that address SN cases?
- a. Yes (please describe)
 - b. No

B. POLICY INFORMATION

1. What is the maximum time allowed between receiving a report and commencing an investigation?
2. What is the maximum time allowed for completing investigations?
3. If a person reported to your program appears to have capacity to consent, is his or her consent required to investigate?
4. What standard of evidence is applied to substantiate/confirm/found allegations? (i.e. preponderance, clear and convincing, etc.)
5. What is the maximum time period that cases opened for intervention can remain open following investigation, and, are there exceptions to this limit?
6. Do you have specific policies regarding SN case handling?
 - a. Yes (please describe and indicate if these appear in state law, regulation, or internal program materials)
 - b. No

C. FY'16 REPORT AND CASE INFORMATION

1. Total number of ALL APS reports received
2. Total number of reports alleging SN received
3. Total number of ALL APS reports screened in for investigation
4. Total number of reports alleging SN screened in for investigation
5. Total number of ALL reports substantiated/confirmed/founded
6. Total number of reports substantiated/confirmed/founded for SN
7. Number of ALL APS clients provided intervention including referrals to other services
8. Number of SN clients provided intervention including referrals to other services
9. Average number of days ALL cases were open for intervention
10. Average number of days SN cases were open for intervention

D. PRACTICE INFORMATION

1. Are reports alleging self-neglect screened or triaged differently from other reports?
 - a. Yes (please describe).
 - b. No
2. Does your APS staff use screening or assessment scales, tests or similar tools (for any purpose) in SN cases? (These may also be used in other types of cases.)
 - a. Yes (please identify and provide tool(s) if possible)
 - b. No
3. Please describe the casework steps in the process used by APS staff to assess client capacity to grant informed consent:
4. Please describe the process used by your program to request or arrange formal capacity evaluations:
5. Does your program have provisions for seeking guardianship or conservatorship for self-neglecting individuals identified as in need of this?
 - a. Yes (please describe)
 - b. No
6. Does APS program staff serve as court-appointed guardians or conservators in SN cases?
7. Do you have contractual or other arrangements with physicians or nurses and/or health care organizations employing them to assist in handling SN cases?
 - a. Yes (please describe)
 - b. No
8. Do you have contractual or other arrangements with behavioral health specialists (such as substance abuse and mental health treatment providers) and/or organizations employing them to assist in handling SN cases?
 - a. Yes (please describe).
 - b. No
9. Do you collaborate with American Indian or Alaskan Native tribes in responding to SN?
 - a. Yes (please indicate which tribe(s) and describe the arrangements)
 - b. No

10. Do you have collaborative arrangements with entities (other than those specified in questions 7, 8, 9 above) to assist in handling SN cases?
 - a. Yes (please list the entities and describe the service(s) they provide)
 - b. No
11. Does your program participate in MDT's, Fatality Review, Hoarding Task Forces or other inter-agency or multi-disciplinary teams?
 - a. Yes (please describe)
 - b. No

E. SUMMARY INFORMATION

1. Do you use one or more innovative practices to prevent or respond to SN cases?
 - a. Yes (please describe)
 - b. No
2. Since 2011, has your program participated in or collaborated on any research projects addressing SN?
 - a. Yes (please describe)
 - b. No
3. Please add any comments or information you would like, including lessons learned or recommendations for preventing or responding to self-neglect cases:

Many thanks for providing this information!!!

Appendix E
SNAPS Tables of Findings

Table 1. Program Funding and Administration

| Funding Source | N | Yes, n(%) | No, n(%) | Average % of Funding from Source |
|---|----------|------------------|-----------------|---|
| Social Services Block Grant | 49 | 28(57) | 21(43) | 19 |
| State General Revenue/Funds | 49 | 39(80) | 10 (20) | 53 |
| Older Americans Act Fund | 49 | 11(22) | 38(78) | <1 |
| Victims of Crime Act Fund | 49 | 2(4) | 47(96) | <1 |
| Local Property tax or mills | 48 | 3(6) | 45(94) | <1 |
| Other | 49 | 13(27) | 36(73) | <1 |
| | | | | |
| Program Administration | | | | |
| State Administered and Operated | 49 | 30(61) | 19(39) | ---- |
| State Supervised and County Administered | 49 | 14(29) | 35(71) | ---- |
| Count Administered | 49 | 3(6) | 46(94) | ---- |
| State Contracts with local agencies to provide APS services | 49 | 8(16) | 41(84) | ---- |
| Other | 49 | 5(10) | 44(90) | ---- |
| | | | | |
| Population Served | | | | |
| Vulnerable adults 18 years and older | 49 | 30(61) | 19(39) | ---- |
| Vulnerable adults 18-59 years and 60+ | 49 | 6(12) | 43(88) | ---- |
| Vulnerable adults 18-64 years and 65+ | 49 | 6(12) | 43(88) | ---- |
| Vulnerable 18-59 years only | 49 | 1(2) | 48(98) | ---- |
| Vulnerable adults 19 years and older | 49 | 1(2) | 48(98) | ---- |
| Adults 60 years and older | 49 | 5(10) | 44(90) | ---- |

The “other” category for funding source includes sources such as the federal grants trust fund, elder abuse intervention prevention program, medical assistance programs, local county governments, vehicle license and sales tax and title XIX funds. For program administration 1 program stated being regionally supervised and 1 mentioned only making referrals to other local agencies. Vulnerable refers to those with a disability.

Table 2: Staffing

| Full Time Employees Statewide | N | Range | Mean |
|---|----------|--------------|-------------|
| APS Administrative and/or management | 42 | 0-206 | 15.54 |
| APS Supervisors | 45 | 0-163 | 24.47 |
| Number of FTEs statewide: APS Caseworkers | 45 | 0-798 | 141.12 |
| Number of FTEs statewide: APS Supervisors + Caseworkers | 44 | 7-856 | 169.35 |
| Number of FTEs statewide: APS Trainers | 38 | 0-13 | 1.59 |
| Number of FTEs statewide: APS Nurses | 34 | 0-52 | 2.65 |

Only 1 state reported having no full time employees dedicated to the program while 2 programs reported not having any full-time supervisors, or full-time caseworkers. Fourteen reported having no full-time APS trainers and 27 reported not having full-time nurses.

Table 3: Self-Neglect Program Information

| Questions | Responses | Yes, n(%) | No, n(%) |
|--|------------------|------------------|-----------------|
| Does your state law identify mandated reporters for self-neglect? | 49 | 39(80) | 10(20) |
| Does the program provide staff with specialized self-neglect training? | 49 | 23(47) | 26(53) |
| Do you have staff identified as self-neglect specialists or subject matter experts? | 49 | 8(16) | 41(84) |
| Does your state APS law allow APS staff to request court orders to gain entry to the dwelling of alleged self-neglecting persons who refuse access to assess their condition? | 48 | 32(67) | 14(33) |
| Does your state APS law allow APS staff to request court orders to remove self-neglecting persons from danger? | 49 | 30(61) | 19(39) |
| Do you track data on self-neglect cases repeatedly reported to your program? | 49 | 18(37) | 31(63) |
| Do you have specific protocol for responding to repeatedly reported self-neglect cases? | 49 | 8(16) | 41(84) |
| | | | |
| What is the maximum time allowed between receiving a report and commencing an investigation? | 48 | | |
| ≤24 hours | | 7(15) | 41(85) |
| 25-48hrs | | 4(8) | 44(92) |
| 49-72hrs | | 6(13) | 42(87) |
| 73hrs-5 days | | 5(10) | 43(90) |

| | | | |
|---|----|--------|--------|
| 6-10 days | | 17(35) | 31(65) |
| Varies by report | | 7(15) | 41(85) |
| 14 days | | 1(2) | 47(98) |
| 20 days | | 1(2) | 47(98) |
| | | | |
| What is the maximum time allowed for completing investigations? | 49 | | |
| ≤15 | | 2(4) | 47(96) |
| 16-30 days | | 11(22) | 38(78) |
| 31-45 days | | 8(16) | 41(84) |
| 46-90 days | | 14(29) | 35(71) |
| 110 days | | 10(21) | 39(79) |
| 120 days | | 1(2) | 48(98) |
| 180 days | | 2(4) | 47(96) |
| No maximum | | 1(2) | 48(98) |
| | | | |
| If a person reported to your program appears to have capacity to consent, is his or her consent required to investigate? | 49 | 16(33) | 33(67) |
| | | | |
| What standard of evidence is applied to substantiate/confirm/found allegations? (i.e. preponderance, clear and convincing, etc.) | 49 | | |
| Preponderance | | 36(74) | 13(26) |
| Needs to be credible | | 3(6) | 46(94) |
| Reason to believe | | 1(2) | 48(98) |
| Clear and convincing | | 3(6) | 46(94) |
| Need for observation and assessment | | 1(2) | 48(98) |
| No formal policy | | 5(10) | 44(90) |

Table 4. Policy

| Questions | Responses | Yes, n(%) | No, n(%) |
|---|-----------|-----------|----------|
| What is the maximum time allowed between receiving a report and commencing an investigation? | 48 | | |
| ≤24 hours | | 7(15) | 41(85) |
| 25-48hrs | | 4(8) | 44(92) |
| 49-72hrs | | 6(13) | 42(87) |
| 73hrs-5 days | | 5(10) | 43(90) |

| | | | |
|--|----|--------|--------|
| 6-10 days | | 17(35) | 31(65) |
| Varies by report | | 7(15) | 41(85) |
| 14 days | | 1(2) | 47(98) |
| 20 days | | 1(2) | 47(98) |
| | | | |
| What is the maximum time allowed for completing investigations? | 49 | | |
| ≤15 | | 2(4) | 47(96) |
| 16-30 days | | 11(22) | 38(78) |
| 31-45 days | | 8(16) | 41(84) |
| 46-90 days | | 14(29) | 35(71) |
| 110 days | | 10(21) | 39(79) |
| 120 days | | 1(2) | 48(98) |
| 180 days | | 2(4) | 47(96) |
| No maximum | | 1(2) | 48(98) |
| | | | |
| If a person reported to your program appears to have capacity to consent, is his or her consent required to investigate? | 49 | 16(33) | 33(67) |
| | | | |
| What standard of evidence is applied to substantiate/confirm/found allegations? (i.e. preponderance, clear and convincing, etc.) | 49 | | |
| Preponderance | | 36(74) | 13(26) |
| Needs to be credible | | 3(6) | 46(94) |
| Reason to believe | | 1(2) | 48(98) |
| Clear and convincing | | 3(6) | 46(94) |
| Need for observation and assessment | | 1(2) | 48(98) |
| No formal policy | | 5(10) | 44(90) |
| | | | |
| What is the maximum time period that cases opened for intervention can remain open following investigation and are there exceptions to the limit? | | | |
| | 49 | | |
| 30days | | 1(2) | 48(98) |
| 30days+ | | 2(4) | 47(96) |
| 45days+ | | 2(4) | 47(96) |
| 60days-120days | | 1(2) | 48(98) |
| 90days+ | | 5(10) | 44(90) |
| 120days+ | | 1(2) | 48(98) |

| | | | |
|--|----|--------|--------|
| 150days | | 1(2) | 48(98) |
| 180days | | 1(2) | 48(98) |
| 180days+ | | 4(8) | 45(98) |
| 365days+ | | 2(4) | 47(96) |
| No limit specified | | 26(52) | 23(48) |
| | | | |
| Do you have specific policies regarding self-neglect case handling? | 48 | 13(27) | 35(73) |

+Programs that have stated limits and allow for exceptions that extend the time to unlimited.

Table 5. Practice

| Question | Responses | Yes, n(%) | No, n(%) |
|--|-----------|-----------|----------|
| Are reports alleging self-neglect screened or triaged differently from other reports? | 49 | 4(8) | 45(92) |
| Does your APS staff use screening or assessment scales, tests or similar tools (for any purpose) in self-neglect cases? | 49 | 37(76) | 12(24) |
| Does your program have provisions for seeking guardianship or conservatorship for self-neglecting individuals identified as in need of this? | 49 | 45(92) | 4(8) |
| Does APS program staff serve as court-appointed guardians or conservators in self-neglect cases? | 48 | 12(25) | 36(75) |
| Do you have contractual or other arrangements with physicians or nurses and/or healthcare organizations employing them to assist in handling self-neglect cases? | 46 | 15(33) | 31(67) |
| Do you have contractual or other arrangements with behavioral health specialists (such as substance abuse and mental health providers) and/or organizations employing them to assist in handling self-neglect cases? | 47 | 13(28) | 34(72) |
| Do you collaborate with American Indian or Alaska Native Tribes in responding to self-neglect? | 41 | 21(51) | 20(49) |
| Do you have collaborative arrangements with entities (other than those specified in questions above) to assist in handling self-neglect cases? | 46 | 20(43) | 26(57) |

| | | | |
|--|----|--------|--------|
| Does your program participate in multi-disciplinary teams, death/fatality review, hoarding task forces or other inter-agency or multi-disciplinary teams? | 49 | 42(86) | 7(14) |
| Do you use one or more innovative practices to prevent or respond to self-neglect cases? | 46 | 14(30) | 32(70) |
| Since 2011, has your program participated in or collaborated on any research projects addressing self-neglect? | 49 | 4(8) | 45(92) |

Appendix F

Selected Findings - APS Program Site Visits to Explore Innovations

About one-quarter of the state APS programs responded affirmatively to SNAPS question E1 (page 6, Appendix D): “Do you use one or more innovative practices to prevent or respond to self-neglect cases?” Analysis of the practices reported as innovative revealed that some were quite vague or, while innovative for the involved program, have been standard in many locales for years. Some of the reported innovations appeared to hold promise for improved APS practice. We selected and explored innovative self-neglect practices in several jurisdictions including Florida and the St. Regis Mohawk Tribe collaboration with New York State APS.

Florida APS

Innovations reported by Florida included tracking outcome data on self-neglect cases and tracking data on repeat self-neglect reports on the same client. Of significant interest, this program also reported having a specific protocol for responding to repeat self-neglect reports. Repeat, or “recidivistic” cases are a concern with the APS field. Of note, a study by Wangmo et. al. (2014) found a 31% recidivism rate in self-neglect vs. 24% rate in abuse cases. The Florida innovation involved utilizing APS Counselors, trained to engage clients in services and assist with clients during an intervention phase of casework, interact with persons re-reported for self-neglect from the start of an APS encounter. In Florida, typically a client reported to APS is initially visited by an APS Investigator and does not see a Counselor until after his or her report has been investigated and is substantiated. Having a Counselor make the initial home visit with the Investigator helped to engage re-reported (or recidivistic) self-neglecting clients in a service plan. These were clients who had received previous, unsuccessful APS intervention attempts.

The innovative practice enjoyed success in avoiding additional re-reports to APS for self-neglect. However, over a period of time it was phased out due to staffing shortages and other complications. Consistently having an APS Counselor available to accompany an Investigator at the initial visit to commence an investigation (which must occur in Florida under a tight time requirement) proved problematic. More adequate funding and staffing patterns would likely make such an attempt to reduce recidivism among self-neglect cases possible.

New York State APS - Saint Regis Mohawk Tribe (SRMT) Collaboration

The information contained here-in is shared with the knowledge and consent of the SRMT APS staff and tribal leadership. The New York State APS Program collaborates with the St. Regis Mohawk Tribe (SRMT) to provide culturally-specific APS services to tribal members. The tribal territory, Akwesasne, is located in both the US (in Franklin and St. Lawrence Counties) and Canada (Ontario and Quebec Provinces). The Mohawks of Akwesasne make up one of the original members of the Five Nations of the Iroquois Confederacy, which is now known as the Six Nations Confederacy or Iroquois Confederacy. About 10,000 tribal members reside in the US portion of the Territory, including about 1400 elders. The St. Regis have operated a tribal government since the early 1800's when the New York State legislature first legally recognized the Mohawk People's chosen representatives. During the 1990's it was recognized that the tribe needed culturally-specific social services due to mistrust of tribal members for off-Territory services and the lack of cultural competence of those services. In 1994 the tribe was authorized by the State Tribal Compact to provide social services in the form of preventive, foster, and adoption services. In 2006 the tribe became authorized by the state to

provide APS services to its members. The SRMT APS program is supported through NYS funds (93%) and tribal funds (7%). It serves older and vulnerable adult tribal members residing in Franklin County on tribal land. The program conforms to the NYS APS program guidelines and is evaluated by the NYS Office of Child and Family Services Bureau of Adult Services. This Bureau recognizes the need for culturally competent and specific tribal services and regards the SRMT APS program as unique. Tribal APS employees receive training from New York state and follow state APS guidelines and eligibility criteria. The tribe employs two APS workers. They report to a tribal program manager who supervises both child and adult protective services. The APS workers are required to complete New York's "New Worker Institute" which protective caseworkers throughout the state receive.

About 75% of the SRMT APS cases involve self-neglect. Many of these cases also entail financial exploitation and abuse. Multiple factors are correlated with self-neglect cases coming to attention on the territory. Numerous dilapidated homes present environmental hazards to their occupants resulting in self-neglect reports. Non-payment of bills resulting in terminated utilities and even eviction is a frequent self-neglect contributor as well as undiagnosed dementia. Medical neglect is common and often correlated with a traditional belief system that rejects Western medicine in total or refuses specific Western interventions such as dialysis. In the Mohawk culture, life is viewed as a journey and death as a natural part of that journey. The traditional belief is that needed medicine will come from the earth and that death is not to be avoided or artificially prolonged.

Factors contributing to self-neglect also include lack of family involvement and separation from family. This is particularly problematic for older adults who are reluctant to rely

on agencies for needed assistance. A large tribal population is resistant to agency involvement as a result of intergenerational trauma and decades of dealing with the government. Events correlated with historical trauma experienced by the tribe include the seizure of native land, forced assimilation (for example, forbidding native language and cultural practices), forced placement of Mohawk children into residential schools, and forced sterilization. For some tribal members, this trauma is expressed in the form of self-neglect of medical, financial, or personal care needs or hoarding behavior. Another cultural factor believed related to self-neglect is the loss of traditional housing arrangements. Mohawks traditionally lived communally in longhouses. Cultural disruption resulted in a transition to people residing separately in individual homes. This has been linked to feelings of loss of purpose and daily living activity.

SRMT APS workers perform typical APS functions: receiving reports of abuse and neglect; investigating alleged abuse, neglect, self-neglect, and financial exploitation; collaborating with tribal police as needed; and coordinating services such as home health care and entitlement benefits. After assessing cases they refer for needed services such as the Three Sisters Program that addresses domestic violence and sexual assault and tribal drug and alcohol programs. Additionally, they serve as SSI representative payees for clients needing that service. The tribe has a Housing Improvement Program where clients needing home remediation are often referred. The APS workers also refer clients to the Tribal Office for the Aging for a variety of transportation, meal, and other senior services. The tribe also operates a Health Services program where clients needing drug and alcohol, mental health, and physical health services may be referred. The tribe has over 50 services available including a cleaning service and a family

support program. Of note, the tribal mental health program provides a culturally based treatment approach.

While the duties performed by the SRMT APS workers are similar to those provided by APS workers across the country, there are important differences in how this culturally-specific and responsive APS program operates. The tribe is a closely-knit community in which members are, for the most part, very well known to each other. As a result, tribal APS reports often contain valuable background information, such as a description of the referred person's lifelong habits and current behaviors that signal possible maltreatment. This information significantly informs report screening and investigation. The program works from a "least restrictive intervention" philosophy in which guardianship is rarely an option and is always the very last resort. The main priority of all casework is preserving clients' rights to self-determination. The Trauma-Informed Care model is used by all tribal services and all tribal support workers are formally trained in this approach. Tribal APS workers assume that referred adults have experienced trauma and follow trauma-informed tenets and practices in approaching and supporting clients. They consult with the client's neighbors, family, and community as collateral contacts. Traditional interventions are arranged for clients desiring them such as tribal healers and medicine persons, healing ceremonies, talking circles, sweat lodges, and culturally-specific mental health treatment. This program actively attempts to avoid re-traumatizing clients. In addition to culturally relevant and specific services, traditional APS methods and services used off-territory are also offered and arranged if deemed relevant to the client.

Tribal APS staff generously collaborated with NAPSA to provide the information contained here. They were asked if they have recommendations for how APS-tribal

collaborations across the country might be improved. They noted that it is rare to find tribes operating their own APS programs. They strongly recommend that tribes work with their state government to create specific tribal APS programs as part of taking back control for their people.

Among the specific recommendations offered are: 1) Maintain a trauma-informed service delivery model, 2) Provide trauma-informed care, 3) Encourage family-based solutions, 4) Keep with traditional teachings and medicines. An example of traditional Iroquois teachings is the concept of “having a good mind” as a main focus and using this approach in all undertakings. This teaching is used by Project Good Mind which serves all tribes in the US and Canada.

NAPSA expresses sincere gratitude to the SRMT and to its APS program Senior Caseworker, Kristin Post their generous collaboration and sharing of the information contained in this report. We are also grateful to Alan Lawitz, NYS APS Program Director, for contributing to and supporting the collaboration of the SRMT with the NAPSA Self-Neglect Project.

Appendix G

Self-Neglect Knowledge, Policy, Practice & Research: Realities and Needs 2019 APS Case Assessment Tools Survey

NAPSA is continuing its Elder Justice ACL-Funded project entitled, 'Self-Neglect Knowledge, Policy, Practice & Research: Realities & Needs'. In 2017 your program completed a more comprehensive questionnaire for this project, "The SNAPS Survey." We were very grateful for your input and are now updating our findings regarding case assessment tools used. All state and territory APS Program administrators are asked to complete this questionnaire regarding case assessment tools, tests, and scales used within their program.

There are two options for submitting your responses to this survey.

1. Type your responses into this word document and email the word document to the NAPSA research team at Jason.Burnett@uth.tmc.edu
2. Enter your data electronically by clicking on the Qualtrics link: https://uthtmc.az1.qualtrics.com/jfe/form/SV_emNE6INiDnmnxnD

We request information regarding ALL assessment tools used by your program in all cases handled - physical, emotional, sexual abuse; caregiver neglect; exploitation; abandonment; etc. Please address tools used to screen or evaluate (1) individuals reported to APS, (2) conditions within the homes of reported individuals, (3) client health/self-care conditions or limitations. Please address tools used to determine if a problem exists (such as cognitive confusion) or to measure the seriousness of problems affecting clients (such as unsafe home conditions) as well as tools used to measure casework progress or lack thereof during intervention.

We want to determine the case measurement tools that are available to APS, how they are used and to what effectiveness, and unmet APS case measurement needs. The findings will inform practice going forward and the project results will be provided to you.

This form is designed to record APS program information. We request that one be completed for each state or territory program. If a question does not apply to your program, please reply "NA". If a question requests data that your program does not track or tabulate, please reply "Not Tracked". The electronic survey version is designed to enable respondents to save their work on incomplete questionnaires and complete at a later time. If you need to save the Qualtrics electronic survey and later complete it, please return to the survey using the link above. Thank you very much!

Please direct questions to: Dr. Holly Ramsey-Klawnsnik, NAPSA Self-Neglect Project Director
Holly.ramsey-klawnsnik@napsa-now.org

Respondent and State/Territory APS Program Information

Q1 First name of person completing this survey

Q2 Last Name

Q3 Title

Q4 Organization

Q5 E-mail Address

Q6 Phone Number

Q7 Do you give us permission to contact you if we have further questions?

Yes

No

Q8 Name of U.S. State or Territory

Name:

Other U.S. 2-digit postal abbreviation:

Q9 Name of APS Program

Information Regarding ALL Tools Used in Program

Q10. Please list ALL of the case/client assessment tools, tests, and scales used in your program to assess alleged victims reported for ANY allegation(s) (i.e. abuse, neglect, caregiver neglect, self-neglect, exploitation, abandonment). (Please provide the full name of each tool.)

Q11. Were any of the tools you listed above developed by your program and/or state?

- Yes
- No - (If your answer is "no", please skip to Q15)
- Unknown
- N/A

Q12. If yes, which tools were developed by your program and/or state?

Q13. Have any of the tools developed by your program/state been validated by research?

- Yes
- No
- Unknown

Q14. Please indicate which tools have been validated by research.

Q15. Are there specific case assessment or measurement tools that your staff has found to be particularly helpful in assessing clients or allegations?

- Yes
- No (If your answer is no, please skip to Q18)
- Unknown
- N/A

Q16. If yes, please indicate which tools your staff has found to be particularly helpful in assessing clients or allegations.

Q17. Please indicate in which ways these tools are considered by staff to be helpful. (Select all that apply)

- Easy to administer
- Easy to interpret
- Brief
- Covered important domains
- Acceptable to clients
- Observational
- Other _____

Q18. Are there specific case assessment or measurement tools that your staff has found to be unhelpful or problematic in assessing APS clients or allegations?

- Yes
- No (If your answer is “no,” please skip to Q21)
- Unknown
- N/A

Q19. If yes, please indicate which tools your staff has found to be unhelpful or problematic in assessing APS clients or allegations.

Q20. Please indicate the ways in which these tools are considered by staff to be not helpful. (Select all that apply)

| | |
|--------------------------|--|
| <input type="checkbox"/> | Too long |
| <input type="checkbox"/> | Staff were not trained to use the tool |
| <input type="checkbox"/> | Not appropriate in most cases |
| <input type="checkbox"/> | Hard to administer |
| <input type="checkbox"/> | Difficult to interpret |
| <input type="checkbox"/> | Clients refuse |
| <input type="checkbox"/> | Other _____ |

Information Regarding Tools Used Specifically in Self-Neglect Allegations

Q21. Which of the tools used in your program are used to assess clients reported for self-neglect? (Please provide the full name of each assessment/tool.)

Q22. Are ALL of these tools listed above used to assess every client reported for self-neglect?

- Yes (if your answer is "yes," please skip to Q25)
- No
- Unknown
- N/A

Q23. If no, please explain why not all of the tools are used to assess every client reported for self-neglect.

Q24. What determines which tools are used to assess clients reported for self-neglect?

Q25. Are there tools that are used to assess EVERY client reported for self-neglect?

- Yes
- No (if your answer is "no," please skip to Q27)
- Unknown
- N/A

Q26. If yes, what are the tools that are used to assess every client reported for self-neglect?

Q27. Are there any tools identified in the training provided to your staff as being more important for validating/substantiating self-neglect allegations?

- Yes
- No (if your answer is "no," please skip to Q29)
- Unknown
- N/A

Q28. If yes, please provide the full name of each assessment/tool provided to your staff as being more important for validating/substantiating self-neglect allegations.

Q29. If a standardized self-neglect assessment tool was available for assessing and validating/substantiating self-neglect, would your program consider adopting and implementing it?

- Yes
- No
- Unknown
- N/A

Q30. Are there any barriers you can think of that prevent or would prevent the adoption and implementation of a standardized self-neglect assessment tool by your program?

Final Questions

Q31. Please upload a copy of all case/client assessment screening tools, tests, or scales used by your program for assessing clients, validating/substantiating allegations of any type, or measuring improvement in client safety or functioning during intervention efforts. Files can be combined into a zip folder to be uploaded.

(Note: If you are filling out this survey in Word format, you will not be able to upload the documents here. You may however, click on the Qualtrics link: https://uthtmc.az1.qualtrics.com/jfe/form/SV_emNE6INiDnmnxnD and upload your files electronically or you can send the tools directly to the NAPSA research team, by emailing them to jason.Burnett@uth.tmc.edu.

Q32. Please provide any comments you would like regarding this project:

Thank you!

Your input on behalf of your APS program is extremely valuable!

Appendix H

Self-Neglect Knowledge, Policy, Practice & Research: Realities and Needs

ACL-Funded Elder Justice Project #90EJIG0008-01-00

Summary of Findings - 2019 Survey - APS Assessment Tools Used

Prepared by: Holly Ramsey-Klawnsnik, Ph.D.
Director of Research & Self-Neglect Project, NAPSA
&
Jason Burnett, Ph.D.
Project Tools Expert & Statistician

Over-all results:

- The survey was returned by 43 of the 53 state APS Program Administrators (81% response rate).
- Two of the 43 respondents did not provide systematic survey response but just indicated several tools that are used in some areas of the state.
- A total of 155 case/client assessment tools were listed by the responding programs as being used. Of these, 98 were reported as used in self-neglect cases (reflecting 88 different tools after duplicates removed).
- Seven (7) programs indicate that the use of case/client assessment tools is not uniform throughout the program, but rather determined by local jurisdictions (such as county programs) or by individual workers or supervisors.
- Three (3) programs reported that they use no case/client assessment tools.

Standardized Tools Reported as Used & Number of Programs Using Them

- Mini-Mental Status Exam - 9 programs using
- Montreal Cognitive Assessment - 4
- St. Louis University Mental Status Exam - 8
- Short Portable Mental Status Questionnaire - 5
- Brief Interview for Mental Status- 2
- Clock Drawing or CLOX: 5
- The Executive Interview (Exit 25) - 1

- Memory Impairment Screen (MIS) - 1
- Mini-Cog - Screening for Cognitive Impairment in Older Adults - 3
- Lichtenberg Financial Decision-Making Scale - 2
- Other tools referencing "Capacity" to decide in title: 5
- Geriatric Depression Scale - 3
- Generic Depression Scale - 1
- Beck Depression Inventory - 1
- PHQ9 - Patient Health Questionnaire (rates depression severity)
- Clutter Rating Scale - 1
- Frost Hoarding Rating Scale - 1
- Katz Independence for ADLs - 1
- Lawton-Brody Instrumental ADLs - 1

| <u>Standardized tools used fall into 4 groups</u> | <u>N Programs Using</u> |
|---|--------------------------------------|
| Cognitive assessments | 49 (some programs must use multiple) |
| Depression assessments | 6 |
| Hoarding assessments | 2 |
| ADLs assessment | 2 |

31 Programs (72%) reported using assessment tools in self-neglect cases

49 tools reportedly used in every self-neglect case

Tools reported as used for Self-Neglect Case/Client Assessment

(Note: It is unclear what some of these tools are - full name not provided.)

SDM (Structured Decision-Making) Intake Assessment

Initial Safety Assessment

Strengths and Needs Assessment/Reassessment

Final Safety Assessment

List of ADLs and IADLS

Determining Vulnerability Intake

Determining Vulnerability Investigation

SDMA (Structured Decision-Making) Safety Assessment

SDMA (Structured Decision-Making) Risk Assessment

SDMA (Structured Decision-Making) Strength and Needs Assessment

Risk Identification and Mitigation Plan

Mini-Cog - Screening for Cognitive Impairment in Older Adults

PHQ9 - Patient Health Questionnaire-9 (assesses degree of depression severity)

AUDIT - The Alcohol Use Disorders Identification Test

GAD-7 - Generalized Anxiety Disorder 7-item Scale

Jump Technology for Neglect

Risk Assessment Tool

Risk Assessment

Needs Assessment

Capacity Assessment

CLOX 1 & CLOX 2 - Clock drawing task to elicit executive impairment

EXIT 25 - The Executive Interview

SLUMS - St. Louis University Mental Status Exam

Short Portable Mental Status Questionnaire

APS Intake Tool

Risk Assessment

Needs Assessment

Strengths Assessment

MMSE - Mini Mental Status Exam

MOCA - Montreal Cognitive Assessment

Risk Assessment Matrix

Investigation Summary and Assessment

Adult Functional Risk Assessment

Clutter Image Rating Scale

Social Assessment

In-Home Safety Assessment

Capacity to Consent To or Refuse Services Assessment

APS Community Evaluation

APS Facility Evaluation

Cognition Worksheet

PSE Risk Assessment (Not certain what this is. It is not a standard tool.)
APS Assessment Form (APS-5)
Adult Protective Services Safety Evaluation Plan
Uniform Assessment Instrument
Risk Assessment Component of Abuse Intake Form
Safety Assessment
Risk Assessment
Protective Services Assessment
Perpetrator Access
Decisional Capacity
Financial Exploitation
Depression Scale
Initial Screening Assessment
Brief Interview for Mental Status (BIMS)
Various non-specified tools
Risk
Frost Hoarding Assessment and Rating Scale
Risk and Safety Assessment
Intake
Overall Initial Risk Assessment
Overall Substantiated Risk Assessment
Updated Risk Assessment
Client Status
Case Plan
Injury Location Chart
Beck's Depression Inventory
GDS - Geriatric Depression Scale
APS Risk Assessment
Capacity Assessment
Cognitive Ability Assessment

Capacity to Consent
Risk Assessment
Functional Assessment
Cognitive Status
Dependency Assessment
Cognitive Screening Tool
Lawton-Brody Instrumental Activities of Daily Living Scale
Katz Independence for Activities of Daily Living Scale
APS Investigative Assessment
Determination of Need - Revised (DON-R)
Nutrition Screening Initiative (part A - Nutrition and part B - Oral Health)
Risk of Recidivism Assessment
Strengths and Needs Assessment

Programs using purchased tools (NCCD, Harmony, Jump) N =10

Tools Developed by APS Programs

63 tools reported by 25 programs as being developed by the program
20 of these tools reportedly validated by research in 5 programs
Programs using in-program developed tools and no others N = 18
Programs using in-program developed tools and other tools N =26

Programs reporting at least 1 tool used is not helpful N=13

54 tools were reported not to be helpful

Number of responses as to why tools ARE helpful:

Easy to interpret- N=18
Easy to Administer – N =22
Brief – N=16
Covered important domain – N=22
Acceptable to clients – N=11
Observational – N=17

Key Comments From Tools Panelists

It appears that a lot of work remains to be done to educate APS programs about existing case/client assessment tools that have been tested. It also appears that more work needs to be done to develop tools that are easy to use for APS caseworkers and that will be acceptable for clients.

I was bewildered to see the variety of tools used from state to state (and sometimes within a state), and I was sorry to see that some programs were still using the MMSE.

The high level of use of untested tools and the vast variety of tools in use around the country speak to an APS system without a common understanding of practice. Diversity in practice is not a bad thing, but I believe there has to be a common understanding of some principles of practice (e.g., tools should be tested; training should be required before tools can be used; tools should only be used for the purpose for which they were created). The implications of a lack of common understanding of these principles include inconsistency in client care; difficulty in testing practice interventions; and difficulty speaking with one voice when it comes to national advocacy.

I believe that good practice combines caseworker judgment with data from tested tools. As a profession, I believe it is time for APS to determine which tools will best assist caseworkers and promote those tools throughout the country. If those tools do not yet exist, the field should advocate for funding at the national level to develop and test tools specifically for APS use. Clients within a state or within the US should be able to rely on some minimum standard of practice from their APS programs.

I'm shocked, shocked, to see that more APS-related research is needed!

The overall results presented in the Summary of Preliminary Findings – 2019 Survey – APS Assessment Tools Used indicate that there is likely a lack of knowledge regarding the value of using a standardized tool, and using it in a systematic way throughout a program. APS workers' responses to the survey show that they want brief, easy to administer and interpret tools that are observational, and that cover important domains, although these are not specified. However, the list of tools used is largely focused on cognitive status, depression, and risk assessment with just a few tools addressing hoarding, mental health and ADLs. This suggests that APS programs

either deal with clients that are usually suffering from some form of cognitive decline, or there is a predisposition amongst workers that bias them in their assessments of client capacity.

Overall the focus of the tools listed in the survey results focus on the client but without attention to their general health, living environment, history of living conditions and personal care, etc. These more “contextual” issues need to be addressed when assessing a client and there are standardized tools that do this.

Programs must ensure that APS workers who are using tools receive sufficient training in their use. This training should be conducted prior to a worker entering the field.

APS program administrators at all levels should be committed to the use of validated tools, even when their use may require a significant change in practice at the individual worker level, and may require more time during the assessment as well as during recording of the assessment results (e.g., data entry into a computerized data base from a paper record).

My thoughts regarding the implications of these findings can be categorized into several areas of action. First, there needs to be a stronger and more “out there” commitment to self-neglect issues, starting at the community level for the public, and through advocacy at the federal and state levels.

As a researcher, what I have gleaned from the survey findings is that the state of data collection related to assessment in particular as well as risk assessment is chaotic. The overall impressions are that there are vast number of tools and various stages of validation and research. There are huge issues about training and the use of these tools.

These findings inform the field regarding APS program practices about how disparate and different they are they also demonstrates that the APS programs around the country are trying their best to evaluate the people reported to them.

Practice recommendations on these findings would be to narrow this down to one or two of the most validated tools or at least of one battery and study that.

Thoughts regarding there implications for these finding for APS program practice going forward is that a uniform set of tools will strengthen the work reputation of Adult Protective Service workers.

The policy recommendations would be to have a uniform tool or battery such that APS workers across counties and across states could communicate with each other. I likened this to a national tool used by the Association of Occupational Therapist of America (AOTA) called the KELS tool, which allows excellent two-way communication with occupational therapists across the United States. APS workers would benefit from a well-recognized and standardized tool.

Appendix I
2019 APS Case Assessment Tools Survey
Tools Panelists Bios

Carol Dayton, ACSW, LISW has focused on services to adults at risk of harm with the goals of improving service delivery systems and creating innovative collaborations that are sustained over time. She is a presenter and published author in the field of aging and elder abuse retired from the Cuyahoga County Department of Senior and Adult Services after serving as Adult Protective Services Chief for 12 years. There, she worked with IT staff to create the initial computer based assessment tool for investigator use. She Co-Chairs the NAPSA Research Committee that has presented several webinars on validated tools for functional capacity as well as TRIO for risk assessment. For the past three years, Carol has served as the NAPSA Board of Directors representative to the project team conducting this study.

Lori Delagrammatikas, MSW is the Executive Director of the National Adult Protective Services Association (NAPSA). She has worked in the field of elder and dependent adult abuse for over 20 years. Lori worked at the San Diego State University providing Adult Protective Services (APS) training throughout California and is credited with the systematic development of what have become the 23 APS core competency training modules used nationally under the auspices of NAPSA. In this position, she worked with national professionals to research and develop training on risk assessment for use by APS professionals. During this same time period, as the chair of the NAPSA Regional Representative Advisory Board (RRAB), Lori collected a wide assortment of assessment tools that were being used by the states in order to provide technical assistance to state programs. Lori has also been the top APS official for the State of California and, during her tenure in that position, she was responsible for revamping the state data collection system. As part of that process, various types of assessment tools were reviewed for potential inclusion in the California data collection system.

Carmel Bitondo Dyer, MD, has served as a clinician, researcher, educator, and administrator for more than 25 years. As executive director of the Consortium on Aging at The University of Texas Health Science Center at Houston (UTHealth) and executive vice chair of the Department of Internal Medicine at McGovern Medical School at UTHealth, Dyer promotes a circle of care concept to deliver comprehensive, age-appropriate care to older adults. Her areas of expertise include preventing elder abuse, especially self-neglect, developing innovative models of health care, and building interprofessional teams that work together on behalf of vulnerable patients. In addition to her executive leadership roles, Dyer is the Roy M. and Phyllis Gough Huffington Chair in Gerontology, Vincent F. and Nancy P. Guinee Distinguished Chair, and Professor in the Division of Geriatric and Palliative Medicine at UTHealth. Dr. Dyer led the development of the

Self-Neglect Severity Scale (SSS), a researched and validated specific self-neglect assessment tool.

Madelyn Iris received her Ph.D. in Anthropology from Northwestern University. She is an Adjunct Associate Professor at the Feinberg School of Medicine, Northwestern University and was the Director of the Leonard Schanfield Research Institute at CJE Senior Life in Chicago, prior to her retirement. Her expertise in elder abuse/elder self-neglect extends back to the mid-1980s when she served as a qualitative evaluator for the north suburban Illinois elder abuse demonstration project. Her work in the development, testing and use of APS case/client assessment tools was conducted in collaboration with Kendon Conrad, Ph.D. and included serving the Principal Investigator for the development and testing of the *Elder Self-Neglect Assessment (ESNA)* funded by the Retirement Research Foundation and as a Co-Principal Investigator on several NIJ-funded projects.

Mary Twomey, MSW is a consultant in elder justice issues. Formerly she was an Aging Program Specialist at the Administration for Community Living, Office of Elder Justice and Adult Protective Services. Previously, Mary was co-director of both the National Center on Elder Abuse and the Center of Excellence on Elder Abuse and Neglect at UC Irvine. From 2000-2007, she ran a local multi-disciplinary Consortium for Elder Abuse Prevention in San Francisco. Before that, she spent 11 years at AARP and, among other things, ran their National Guardianship Monitoring Project. Mary's interest in aging and elder justice issues was kindled when her grandparents came to live with her family when she was a child. She has a Master's degree in Social Work with a concentration in gerontology.

Appendix J

Examining the State APS Program Definitions of Self-Neglect

Collected via the 2017 NAPSA SNAPS Survey

Analysis by: Carol Dayton, ACSW

In considering the question of when and why the government, in the form of APS programs, should be mandated to check on the individual welfare of its citizens, a number of questions arise. In the majority of the Adult Protective Service state programs, investigations of self-neglect reports that have been screened in are mandated, meaning that investigations of how well reported individuals are taking care of themselves will be conducted even in the absence of their permission or request. In view of the strong belief reflected in law and cultural values regarding self-determination and privacy, the circumstances that result in the requirement to send a social service staff member to a person's home to inquire about the well-being of that individual must be prompted by extraordinary circumstances. This review of self-neglect definitions across the country is focused on elements in those definitions that result in an investigation through face-to-face contact, often an unannounced arrival at the person's door. What alleged condition is sufficient to result in this intrusion? What characteristics of the individual are sufficient to trigger an investigation? What level of danger is necessary, often in the absence of any crime and no alleged perpetrator? In the language of only one state's definition, the perpetrator and the victim are the same person in self-neglect cases. Should one instance of self-neglect trigger an investigation? In one state, it is specifically stated that this will be sufficient.

In contrast to the allegations of physical/sexual/emotional/financial abuse and caregiver neglect, it is unique in investigating self-neglect that the assessment is to measure the degree of harm that is occurring, and whether it is sufficient to warrant a plan for protective services. This is in clear contrast to the question of whether harm is occurring when investigating the yes/no question of whether a physical injury or financial loss has occurred. Regarding self-neglect, the question is not whether one is always meeting every need fully, but whether the failure to meet essential needs as defined in each state warrants an investigation, a protective service plan and possible legal interventions, such as guardianship.

It is important to note that for four Adult Protective Service programs in the country, there is no definition of self-neglect and therefore no mandate to report or investigate such an allegation. Another program that does have a self-neglect definition does not open an

investigation, but offers the person described as self-neglecting preventive services and/or completes an assessment of the person and situation.

The questions:

What alleged condition is sufficient to warrant this intrusion?

There is variation across the 49 states that provided definitions of self-neglect, with some being more explicit than others. “Failure to provide (for essential needs)” is the most common phrase, found in twenty-three state definitions applied by APS programs. However, in five programs “failure to avoid” self-neglect is used, implying there is a competent understanding of one’s needs as well as the refusal. One program adds a “lack of desire” to provide for essential needs to the definition, which also implies it is a personal choice. In addition, in one instance it is noted that self-neglect can occur while also receiving services, implying either a lack of cooperation with services and/or an inadequate offer of services. The terms “action or inaction” is in two definitions, and “acts or fails to act” is in four definitions. These indicate not only a passive lack of care, but also the presence of behaviors that can result in self-neglect, capturing situations of hoarding, for example. In two programs living alone is a condition in the definition. Case examples appear to contradict this requirement, such as when two siblings share a home, neither assuming the role of caregiver for the other, and both deteriorate medically in the absence of any care.

What characteristics of the individual are critical to trigger an investigation?

Nineteen states require that the neglectful events are the result of "mental or physical impairment" or "diminished capacity" thereby explicitly or implicitly excluding life style practices. The state definitions regarding self-neglect vary regarding the issue of personal choice. Regarding the nineteen state definitions, five explicitly exclude "life style" or "personal choice," while 14 states have the requirement that the neglect be the result of mental or physical impairment or inability, thereby implicitly excluding life style or personal choice. Three states exclude medical decisions which otherwise might be deemed neglect but are based on religious practices, and two states exclude end-of-life choices for individuals with terminal illness.

Two programs noted that self-neglect also may be the result of not being “able to obtain (essential care) due to circumstances outside of own control.” This indicates that extreme poverty and lack of resources may be the cause in contrast to a change in the person’s capacity to make decisions or act on decisions to provide for care of self. Another example is the plight of undocumented immigrants who cannot obtain public benefits and live in extreme poverty.

“What level of danger is sufficient to require an investigation?”

Although some definitions are vague, all indicate that suffering and significant harm to the well-being of the individual is sufficient. A few states simply use broad terms, indicating neglect of “welfare,” or “meeting basic needs.” Other states enumerate a variety of specific areas of neglect. Listed are the words and how often they were used by states to describe the level of danger due to neglect: health or physical health-36, mental health or mental illness-29, food-20, shelter-19, clothing-16, safety-15, medical care-13, well-being-11, welfare-5, finances or financial affairs-5, self-care-4, water-4, support-3, meeting basic needs-3.

Several definitions describe the alleged harm as physical injury and/or imminent danger that may result in the risk of death. Nine states require "actual injury," "imminent danger," "immediate risk" or other similar language to trigger a finding of self-neglect. An additional six states require that the neglect "threatens well being" The remaining states are silent regarding these issues, thus implying that a finding of self-neglect can be triggered even if the situation is not imminent or life-threatening.

In summary, the forty-nine programs that provided language regarding their self-neglect definitions at the time of the SNAPS 2017 survey describe the need for an APS investigation upon receiving and screening in a report of a vulnerable adult unable to provide for his/her own basic needs and at grave risk of significant harm to health and even survival.

**Appendix K.
Tribal Collaborations Table**

**“Self-Neglect Knowledge, Policy, Practice & Research: Realities & Needs”
AOA Elder Justice & Adult Protective Services Elder Justice Innovation project
awarded to
90EJIG0008-01-00 National Adult Protective Services Association (NAPSA)**

**Table of State APS-Tribal Collaboration
Self-Neglect APS (SNAPS) survey responses to:
“Do you collaborate with American Indian or Alaska Native tribes in responding to
SN?”**

May 31, 2017

| State APS Program | Person Completing SNAPS | Tribes with Formal APS Agreements | Tribes with Informal APS Collaboration | Comments |
|-------------------|--|---|--|---|
| Alabama DHS | Doris Ball, Director APS doris.ball@dhr.alabama.gov 334-242-1355 | Poarch Band of Creek Indians, Escambia Co. collaborates with county APS program, but does not operate a tribal program. Have a well-funded social services program that assists with APS cases. | | Tribal APS helps adult PBCI Tribal Members and families with general welfare, family issues, and adult abuse and neglect investigations and protective services. AL SNAPS includes tribal case numbers. |

| | | | | |
|------------------------------|--|---|---------|---|
| Alaska APS HSS/DSDS | Kelda Barstad, Health Program Mgr. III kelda.barstad@alaska.gov 907-269-3677 | The Kenaitze Tribe is a formal APS program designee | Many | The Kenaitze accept reports of harm to elders and adults with disabilities & partner with APS. Many other tribes help with home visits and services |
| Arizona APS | Alfredo Reyes, Quality Assurance Manager areyes@azdes.gov 602-542-1414 | | | Arizona APS investigates reports, including those for SN, upon written invitation by the tribal council |
| California APS | Lori Delagrammatikas, APS Liaison Lori.Delagrammatikas@dss.ca.gov 916-653-1865 | | | Some counties have arrangements with local tribes |
| Connecticut DHS | Dorian Long, Social Services Program Admin. dorian.long@ct.gov 860-424-5964 | The Mohegan and the Mashentucket tribes | | We have agreed to contact tribal health services |
| Iowa Dept. of Human Services | Catherine Stack, Dependent Adult Protection Program Manager cstack@dhs.state.ia.us 515-281-5392 | | Several | We collaborate when the person has a tribal affiliation. This primarily occurs in NW corner of Iowa |
| Maine APS | Sheryl Nadell, Associate Director, Office of Aging and DS Services Sheryl.nadell@maine.gov 207-286-2630 | | | I do not know specifics |

| | | | | |
|--|--|--|--|--|
| <p>Montana Adult Protective Services</p> | <p>Michael Hagenlock, APS Bureau Chief mhagenlock@mt.gov 406-444-9810</p> | | | <p>MT has 7 reservations; Blackfeet Tribe of the Blackfeet Reservation, Chippewa Cree Tribe of the Rocky Boy's Reservation, Confederated Salish & Kootenai Tribes of the Flathead Reservation, Crow Tribe of the Crow Reservation, Fort Belknap Tribes of the Fort Belknap Reservation, Fort Peck Tribes of the Fort Peck Reservation, Little Shell Chippewa Tribe (state recognized), and Northern Cheyenne Tribe of the Northern Cheyenne Reservation. Each reservation is a Sovereign Nation; governing themselves according to their Tribal law. APS respects this and reports to the Tribal APS worker or requests permission from Tribal Council to investigate on Tribal land. Tribal APS workers also call APS if assistance needed.</p> |
| <p>Nebraska</p> | <p>Sherri Haber, CFS Administrator Sherri.haber@nebraska.gov 402-471-7989</p> | | | <p>We collaborate with Winnebago, Santee Sioux & Omaha tribes</p> |

| | | | | |
|--|--|---|-----------------------|---|
| Nevada EPS | Carrie Embree, Social Services Chief clembree@adsd.nv.gov 775-687-0517 | | | We collaborate if permission is granted by the tribe |
| New Jersey APS | Jennifer Mills, APS Statewide Coordinator Jennifer.mills@dhs.state.nj.us 609-588-6555 | | | Possibly from county to county depending upon individual county resources. This has not been established statewide. |
| New Mexico Aging and Long-Term Services | Peggy Gutierrez, APS Division Director peggy.gutierrez@state.nm.us 505-841-4502 | Agreements in place with 18 tribes including: Navajo Nation (1) Pueblos (14) Apache (3) | | APS must have permission from Tribal Governor to intervene. |
| New York Office of Children and Family Services | Alan Lawitz alan.lawitz@ocfs.ny.gov 518-402-6782 | St. Regis Mohawk Tribe Kristin Post, Senior APS tribal caseworker, Kristin.Post@dfa.state.ny.us | | St. Regis Mohawk is a lawful APS unit funded by NY APS. NY APS oversees and provides training and technical assistance. |
| North Carolina APS | Rena Minor, APS Consultant Rena.minor@dhhs.gov 919-855-3464 | | Eastern Band Cherokee | Assisting Eastern Band Cherokee Indians with development of tribal code & practice |
| North Dakota VPS NDDHS Aging Services | Michelle Gayette, Elder Rights Program Administrator, NDDHS Aging Services mgayette@nd.gov 701-328-4613 | | 2 | We have MOUs with 2 of our reservations for all cases. |

| | | | | |
|--|---|-----------------------|--------------------------|--|
| Oklahoma APS Dept of Human Services | Gail Wettstein APS Director Gail.Wettstein@okdhs.org 405-522-5517 | Osage | 4 tribes | By MOU with collaborate with the Osage. In practice with Choctaw, Chickasaw, Cherokee, and Citizens Pottawatomie |
| Oregon DHS Aging and People with Disabilities | Valarie Eames, Policy Analyst valerie.m.eames@state.or.us 503-945-5884 | Some | Some | For both abuse and self-neglect, MOUs with some tribes or informal arrangements with tribal police, MDTs, or services for tribes |
| South Dakota Long-Term Services and Supports | Cassie Lindquist, Program Specialist Dept of Human Services Cassie.Lindquist@state.sd.us 605-773-3656 | | | Our division works with all 9 reservations in S. Dakota |
| Texas Adult Protective Services | Angela Medina, Management Analyst angela.medina@dfps.state.tx.us 512-438-3187 | | Various | With various tribes, as necessary |
| Washingto n Aging & Long-Term Support Admin. | Carol Sloan, APS Program Manager sloancs@dshs.wa.gov 360-725-2345 | 6 | | Agreements with 6 tribes. |
| Wisconsin Dept. of Health Services | Doreen Goetsch, APS Coordinator doreena.goetsch@wisconsin.gov 608-266-2568 | Some counties have | Some counties have | The counties that have tribes either have an MOU or decide between them who responds |

APPENDIX L

STAFF AND CONSULTANTS Project Year-One

STAFF

Holly Ramsey-Klawnsnik, Ph.D., NAPSA Research Director, Project Director (65% FTE)

Duties: Monitor and insure ongoing project progress, organize and participate in all project components, serve as liaison to ACL, NCPEA, and project consultants, prepare project reports

Trudy Gregorie, NAPSA Executive Director, Project Fiscal Manager (10% FTE)

Duties: Oversee fiscal project management, prepare fiscal reports, insure project interface with other NAPSA functions, coordinate NAPSA Board of Directors consultation

Andrew Capehart, NAPSA Assistant Director, IT Specialist & Content Expert (25% FTE)

Duties: Oversee all IT project aspects, lead in conducting Self-Neglect APS System Assessments, make site visits, assist in NAMRS data analysis, organize conference self-neglect track

Kathleen Quinn, Content Expert (15% FTE)

Duties: Serve as APS, self-neglect & NAMRS expert, contribute to all project components including conducting site visits, writing reports, and reviewing documents

CONSULTANTS

NAPSA Board of Directors & Regional Representatives (in-kind 36 hours monthly)

Duties: Provide ongoing consultation particularly on the development, piloting, administration, and analysis of the Self-Neglect APS (SNAPS) Assessment, review project reports

National Committee for the Prevention of Elder Abuse (NCPEA) (25 hours monthly)

Patricia Brownell, Ph.D., Consultant & NCPEA liaison (15 hours monthly)

Duties: Lead the 20-year self-neglect literature search & analysis, co-author lit search report, consult on other project components, oversee consultation by NCPEA Board members (Drs. Georgia Anetzberger, Margaret Baker, Mary Beth Morrissey, Elizabeth J. Santos, Pearl Berman, 2 hours each monthly)

Jason Burnett, Ph.D., Statistician & Research & Tools Consultant (20 hours monthly)

Duties: Contribute to design of project tools and conduct of literature search & analysis, lead quantitative analysis of SNAPS findings and NAMRS data, contribute to project reports

William Benson, Policy Consultant (15 hours monthly)

Duties: Contribute to the design of methods and tools to best evaluate existing and needed state and national self-neglect policies, prepare a comparative analysis of APS statewide self-neglect policies, review project findings as a policy advisor

International Association for Indigenous Aging (IA2) (6 hours monthly)

Dave Baldrige, Native American Consultant

Duties: Contribute to project components to achieve inclusion of information regarding indigenous people, connect project team to native American APS programs