

# Elder Justice Innovation Grants

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Program Specialist

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# Overview

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- The Elder Justice Innovation Grants are designed to the develop and advance the knowledge and approaches of emerging issues related to elder justice.
- Grants are for 2 years - 2016-2018
- One area of focus for the 2106 grants was self-neglect.
- The Older Americans Act defines self-neglect as:
  - “[An] adult’s inability, due to physical or mental impairment or diminished capacity, to perform essential self-care tasks including -
  - (A) obtaining essential food, clothing, shelter, and medical care;
  - (B) obtaining goods and services necessary to maintain physical health, mental health, or general safety; or
  - (C) managing one’s own financial affairs.

# Goals of the Innovation Self-Neglect Grants

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- Improve understanding of the population of people who self-neglect.
- Expand knowledge about the responses by APS and other providers to self-neglect.

# Awardees:

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## Benjamin Rose Institute

- Will increase the knowledge of risk factors and interventions for self-neglect among older **adults** and **persons with disabilities** to prevent it from occurring or re-occurring.

## National Adult Protective Services Association

- Will examine self-neglect to contribute to the developing evidence-base and inform research, policy and practice.

## Rush University

- Will improve the predictors of elder self-neglect in diverse community populations.



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

Project Director: Holly Ramsey-Klawnsnik, Ph.D.

Presented: August 2018 - NAPSA Annual Conference

# Funding

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- DHHS ACL Elder Justice Cooperative Agreement
- 90EJIG0008-01-00

# Goal & Objective

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- **Goal:** To contribute to the developing self-neglect evidence knowledge base and inform research, policy, and practice
- **Objective:** To significantly enhance existing knowledge regarding responses of APS and other programs to self-neglect

# Overall Task:

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- Systematically examine nationwide APS self-neglect policies and practices, as well as existing research, using mixed methods and a multi-pronged approach



# Project Team – NAPSA Staff

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- Trudy Gregorie, Executive Director
- Andrew Capehart, Assistant Director
- Dr. Holly Ramsey-Klawnsnik, Director of Research

# In-Kind NAPSA Contributors

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- Board of Directors
- Board Rep to project team: Carol Dayton, ACSW, LISW-S
- Regional Representatives

# Subcontractors

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- Jason Burnett, Ph.D.
- Pat Brownell, Ph.D., NCPEA
- Kathleen Quinn
- William Benson
- Dave Baldrige, International Association for Indigenous Aging

# Project Components

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- Conduct systematic SN literature review
- Conduct national survey research re: APS response to SN
- Explore innovative APS SN practices and collaborations

# Component #1. Literature Review

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- A systematic review of SN research literature published over the past 20 years within the US has been conducted
- Research articles meeting inclusion criteria have been analyzed
- The review reveals the current state of SN research including key findings, gaps & overlooked areas
- The results provide a bench point for considering APS SN practices

# Component #2. National Survey Research

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- We created the SNAPS (Self-Neglect APS) questionnaire and administered it to gather FY '16 state-by-state APS SN policies, practices, and tools
- We achieved a 100% response rate from state APS programs
- We are quantitatively and qualitatively analyzing data to assess:
  - APS program response to SN cases including tools used
  - Extent of SN cases referred to APS & outcomes
  - Significant correlations and associations to inform policy and practice

# Component #3. Innovative Practices

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- SNAPS responses enabled us to identify innovative APS SN practices, including collaborations.
- We explored selected practices via limited site visits.
- We are analyzing resulting qualitative data.
- Results will provide a snapshot of innovative APS practices and illuminate practice and research implications & needs.

# Project Status Month 11 of 12 - We Are:

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- Carefully analyzing and considering all data and the confluence of findings
- Preliminary findings & trends are emerging, but we are avoiding premature conclusions or dissemination
- Conducting a national SN Think Tank & conference track to promote discussion and initiatives
- Needing time to complete analysis, interpretation and dissemination.





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**We look forward to providing full findings and contributing to their application to improve self-neglect policy, practice and research.**

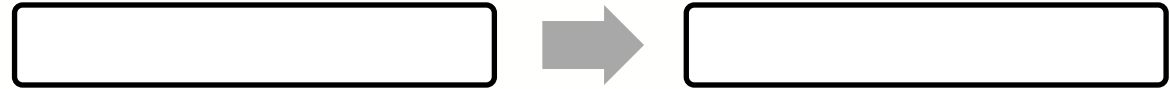
# Predictive Index for Elder Self-Neglect in Diverse Populations

Stephanie Bergren  
Project Coordinator  
Rush Institute for Healthy Aging

- Goal: to improve the prediction process regarding elderly SN by leveraging and expanding existing research and creating a robust predictive index.
- The team: Principal investigators (XinQi Dong, Kumar Bharat Rajan), consultants, project coordinator, data analysts, research assistants, staff, and volunteers.

- Specific Aims:
  1. To develop a predictive index
  2. To examine the racial/ethnic differences of the index among white, AfAm, and Chinese cohorts
  3. To explore the social and cultural context of SN from older adults and family member regarding the barriers, challenges, and potential of prevention and intervention in diverse populations.
- Final Products:
  - Predictive index
  - Qualitative and quantitative data of SN seniors and family/caregiver

- Incident SN



- Datasets from two longitudinal epidemiology studies

- The Chicago Health and Aging Project (CHAP)

- Baseline: 6,158 Chicago residents over 65 years old
- In-person home interviews every 3 years since 1993

- The Population Study of Chinese Elderly (PINE)

- Baseline: 3,157 Chinese people over 60 years old in Chicago
- In-person home interviews every 2 years since 2011

- Dependent variables
  - Onset of SN incidence calculated using two cycles of data from each dataset
  - SN Phenotypes: house needs repair, unsanitary, hoarding, Inadequate Utility, poor hygiene
- Potential risk domains
  - 1) Social-demographic, 2) culture, 3) general well-being, 4) health behaviors, 5) medical conditions, 6) cognitive function, 7) physical function, 8) social network and support, 9) psychological well-being
- Analysis procedure
  - Model development
    - Use multiple methods to select predictive variables in multivariate models
    - Categorize the candidate predictive variables to improve its usefulness by performing bivariate analyses
  - Validation
    - Test accuracy of the models in a validation cohort (30%) of the datasets

Candidate variables predicting overall self-neglect

	CHAP	PINE	Poor hygiene-PINE	Inadequate utility-PINE
1.	Race, income, age	Years in the neighborhood	Sex, living with spouse, household compositions, children,	
2.				Discrimination experience
3.		QoL	Self-reported life quality	QoL, OHS
4.	Smoking, drinking, aspirin intake		smoke	
5.	High blood pressure	Stroke	Hospitalization past 2 years	Respiratory symptoms
6.			Digit back test, NAGI test, GlobCog	GlobCog
7.	Physical activity, use of hearing aid, reading/near vision	Physical activity, activities of daily living	Physical activity	
8.	Social engagement	Social support from family, Positive social support, negative social support		Social engagement
9.	Stress	Stress, personality-neuroticism, loneliness	personality-neuroticism, religious activities	conscientiousness, stress, religious activities

- 300 participants: 150 people over 50 years old with self-neglecting behaviors; 150 key family members or caregivers
- Frame: safety and independent living
- Diverse populations
- Multilingual research assistants:
  - English, Mandarin, Cantonese, etc.



## Seniors

- Socio-demographics
- Life events
- Sleep, Oral Health, Diet
- Healthcare
- Cognitive function
- Decision making capacity
- Social well-being
- Elder abuse and caregiver neglect
- Intergenerational relationships
- Psychological well-being
- Environment observation and post interview summaries

## Family Members/Caregiver

- Socio-demographics
- Life events
- Social well-being
- Normative solidarity (Filial Piety)
- Caregiving
- Mistreatment experience (child abuse, IPV)
- Psychological well-being
- Environment observation and post interview summaries

- Semi-guided interview
- Main questions for seniors
  1. There are those who are concerned that the way you live threatens your own health and safety, what do you make of this?
  2. As you go through the day in providing for yourself necessities like food, clothing, housing, medical care, general safety etc., which of these areas do you feel you need help with to ensure your health and safety?
  3. In order to minimize the potential threats to your health and safety, what do you think would help?
  4. If we assign someone to work with you (e.g., a social worker, case worker), could you describe what type of person would be most helpful and acceptable?
  5. Given the areas that you mentioned as needing assistance, how, if any, can health care professionals help?
  6. What do you know about services in this regard in your community?
  7. What do you think of your children's role in reducing threats to your health and safety?
  8. How, if any, other family members (other than your children) should play a role in reducing threats to health and safety of seniors who need assistance with daily activities?
  9. You mentioned some of your previous experience such as XX, XX, and XX, how do you view its relationship to who and where you are right now?

**Question: If we assign someone to work with you (e.g., a social worker, case worker), could you describe what type of person would be most helpful and acceptable?**

Responses 1:

*The person should be a person with a sense of humor, that's what I love, sense of humor and it would be, put love in what they do... I used to tell my daughter, or anybody, if they, when they're washing dishes, they're not washing dishes properly, they're boom boom. I said, there's no love in what you're doing, you know you have to care. You know homemaker you have to care, you can't just look at something and disregard it...if a person doesn't have any pride in what they're doing then I don't like them. Cuz they, they just, they just agitates me...*

Responses 2:

*A person with experience with mental health issue, depression is a bitch, and I have had it since adolescence...my daughter and my grandchildren...and in their faith, suicide is a sin, you don't have the right to take your life. No matter how painful it feels sometimes (cried paused interview)...it is very hard for people don't have a understanding...I think one of the most important thing that will help...my uncle...he listened, with interest, without judging, or calling us stupid...that helps me... the difference between life and death is...(crying)...someone who can take the time to listen to them...I made everything bad here, but I listen.*

Responses 3:

*I need someone who can translate for me to the doctors, I can take the bus to the hospital, but I need translations. I can't take care of that without translations, which caused me dizziness...I need to do gastroscope, you know how terrible it can be, I'd be dizzy because I can't eat before that. If there is someone who translate for me and the doctor, that will at least make me feel less anxious... I don't know how to talk to the doctors, so just need someone help with the gastroscope.*

**Question: What do you know about services  
in your community?**

**Responses 1:**

*They're geared to mostly safety, but there's really no...if a service were doing more than just sitting here you know... the service to me is that it's difficult, the service is difficult...I guess we have a lot of children's things in the area, but uhh, my point is I know of, we got the Caps meeting, we got seniors meeting, that kind of stuff, but you gotta go somewhere every month to do it.*

**Responses 2:**

*No, I mean, no. well, the place I stay, they do have a, what to say, a physical doctor? Pharmacist came in? she talked to me, but I don't think I can open up to her. I won't be comfortable. There are too many people to do so many jobs, they don't want be bothered what at front. Like other words, to explain some, I tried, I don't know how long to give me some help services through my cell phone. The only thing I got was that people tell me they couldn't help me. or send me to somebody else who they can tell me we can't help you. You gotta understand those people's job whatever.*

## Challenges

- Implementation
  - Consulting advisory board
  - Coordinating an interdisciplinary team
  - Linguistically and culturally competent staff
- Data analysis
  - Strategies: Harmonized vs. Separated
  - Complex model development
- Field data collection
  - Identify participants
  - Interview issues

## Next Steps

- Expand recruitment
- Ongoing training and weekly trouble shooting meeting with interviewers
- Select model with the strongest predictive accuracy
- Increase applicability of the indices
- Validation of the indices

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Thanks!

# Understanding Self-Neglect in Healthcare Patients and Developing a New Intervention to Prevent It

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WellMed Charitable Foundation<sup>3</sup>

Presented at the Annual Conference of the National Adult Protective Services Association (NAPSA),  
Milwaukee, WI

August 28, 2017

# Our Project Collaborators

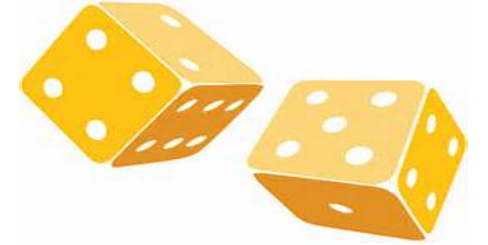
1. Benjamin Rose Institute on Aging – lead
2. WellMed Charitable Foundation & WellMed Medical Management – project site
3. TX Dept. of Family & Protective Services - APS
4. Consultant: Dr. Georgia Anetzberger
5. Elder Justice Coalition





# RESEARCH METHODS

- 2 Regions of Texas
  - San Antonio – HQ of WellMed; largest market
  - Corpus Christi – another large market
- WellMed Primary Care Clinics: matched in each region
- Clinics randomly assigned to intervention & comparison groups
- Sample of community dwelling patients in both groups:
  - Selected based on risk factors for SN: cognitive impairment; depression; and limitations in ADLs etc.



# COMPARISON CLINICS: RECEIVE USUAL CARE AT WELLMED

- Follow protocols developed in 2012-2016 Elder Abuse Prevention Grant funded by ACL
- Elder Abuse Suspicion Index – embedded in EMR
  - Patients suspected of abuse, neglect & exploitation (ANE) reported to APS
  - Those at-risk referred to social workers at WellMed
  - Provide all patients with educational materials on ANE
- Embedded APS worker – resource for clinicians

# INTERVENTION GROUP: SOCIAL WORKER INVOLVEMENT

- Hired two social workers (SWs)
  - One for each region
- Comprehensive training on self-neglect (SN)
- Conduct baseline interview (Time 1) at home
- Includes assessment for Elder SN and ANE
- If SN or ANE is suspected, SW makes a report to APS
- APS:
  - APS takes over and follows 'usual' protocols:
  - Checks for eligibility
  - Conducts investigation
  - Validates case or not
  - Provides services – least restrictive alternative
  - Closes case



# INTERVENTION GROUP: PREVENTION OF SN and ANE

- For patients with risk factors but not SN yet (or ANE), SW:
  - Develops plan of care
  - Links patients to home- and community-based services or to residential care settings, if needed
  - Continues follow-up over a six-month period



# EVALUATION DETAILS

- Expect to have 414 patients in both the intervention and comparison groups (207 in each group).
- Baseline Interview
  - Intervention Group: conducted at home
  - Comparison Group: conducted at the primary care clinic or senior center attached to clinics
- Post-test for both groups:
  - Six months after completion of baseline
  - Staggered basis

# EXAMPLES OF OUTCOMES

Differences between intervention & comparison group patients:

- APS:
  - Number of reports to APS on SN and ANE
  - Recidivism to APS
  - Types of services
- WellMed:
  - Case management reports of services
  - Overall healthcare utilization & costs
- Benjamin Rose:
  - Psycho-social well-being, e.g., depression, anxiety, quality of life
  - Services--Type and dosage (intensity) referred to and followed through by patient
  - Likelihood of remaining at home/in the community

# PROGRESS TO DATE

- Business contracts/agreements: Signed between collaborating organizations
- DUA agreements: Signed with TX APS; in process with WellMed
- Training on SN: Completed
- Patient Interview Schedules: Finalized; electronic data collection
- New hires: BRIA - hired & trained; WellMed - social Workers/interventionists hired; interviewers for comparison group being hired
- IRB approval: Obtained
  - Consent forms developed for patients with/without legal guardians
  - Pilot-testing completed with senior center participants in Ohio
  - Evaluation tracking database being designed
- Spanish translation: In process for consent forms & questionnaires
- Field Operations: BRIA to visit TX to conduct training of social workers and research assistants in September

# Questions





# Contact Information

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# Wrap-Up and Discussion – Aiesha Gurley, ACL

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- Significance of the projects as a body of work
- Themes across projects
- Audience Q & A

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