

Hoarding Disorder: Evidence-based Collaboration and Support for Aging in Place

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Full Life™



Learning Focus

1

Identify the fundamental features of hoarding disorder and distinguish the myths and truths that dispel them

2

Understand the foundational concepts of Cognitive Rehabilitation and Exposure/Sorting Therapy (CREST) and Occupation-based Interventions

3

Recognize the foundational concepts and goals of Aging in Place

4

Takeaway strategies and tools and an opportunity to influence national policy

Welcoming and Holding Space

- ▶ This is collaborative work, and all work is based on the work of those who came before us
- ▶ Culture of feedback and lifelong learning
- ▶ Honor experience and wisdom
- ▶ Honor experience and wisdom in this space
- ▶ Humble to experiences when wisdom has yet to be achieved
- ▶ Hold our humanity in this work
- ▶ Acknowledge how the systems in which we operate hurt individuals

(Light & Johnson, 2024)

Language Matters!

Person
who
hoards

Clutter

Home and
Life
Hygiene

~~HOARDER~~

~~TRASH~~

~~SQUALOR~~

Person First Language



LAKEVIEW
NEW BASIN
CANAL PARK

Resale Business
Local Businesses

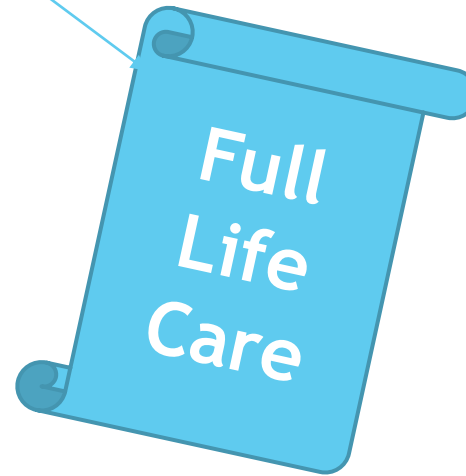
Seattle Housing Authority (SHA)



Snapshot

37,590	Individuals served
8,609	SHA owned/managed units
8,615	Tenant-based vouchers
3,524	Collaborative Housing units

(SHA, n.d.)





Aging &
Disability
Services

Behavioral
Health &
Wellness
Providers

Full
Life
Care





- 1 WHEN: Pre - 2021
WHO: Inspectors, maintenance, PMs, & service providers
WHAT: all reported the same thing: some units had too much stuff; everyone involved is overwhelmed.
- 2 WHEN: 2021
WHO: SHA Inspectors
WHAT: Asked to start using the Clutter Image Rating Scale in homes that were above a "4."

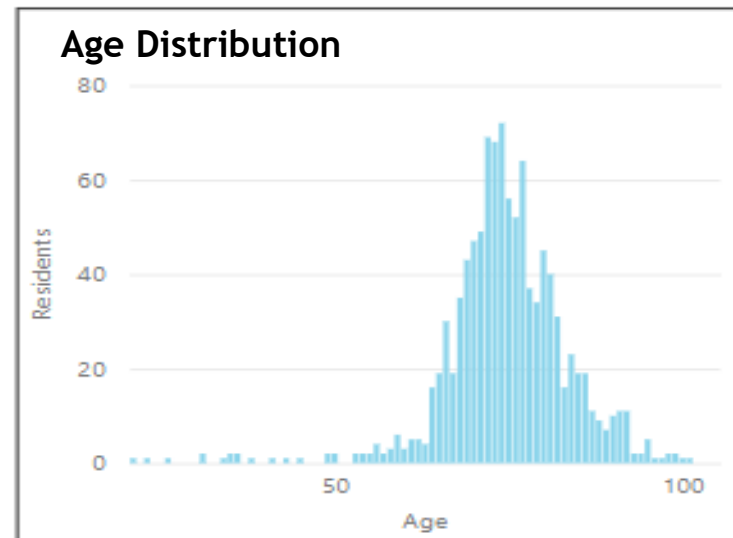
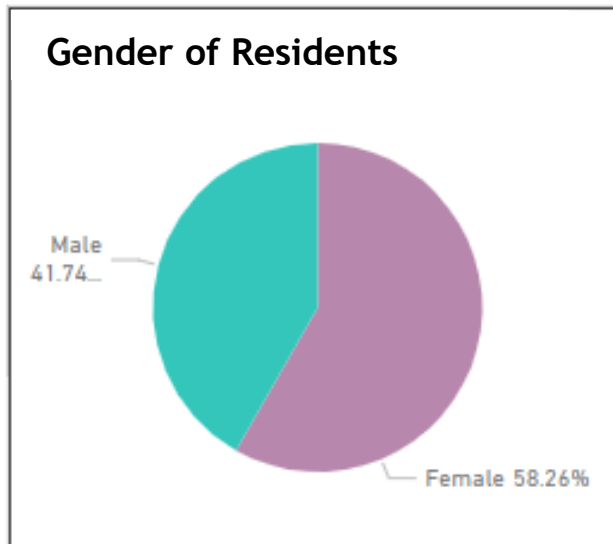
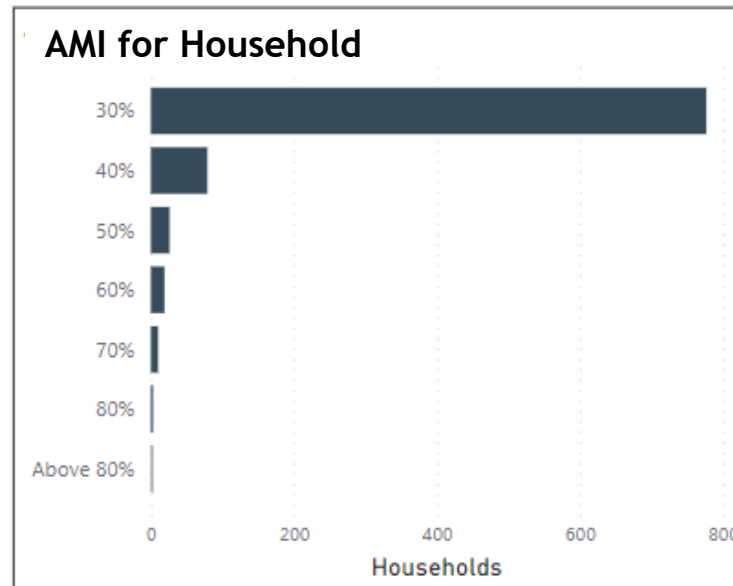
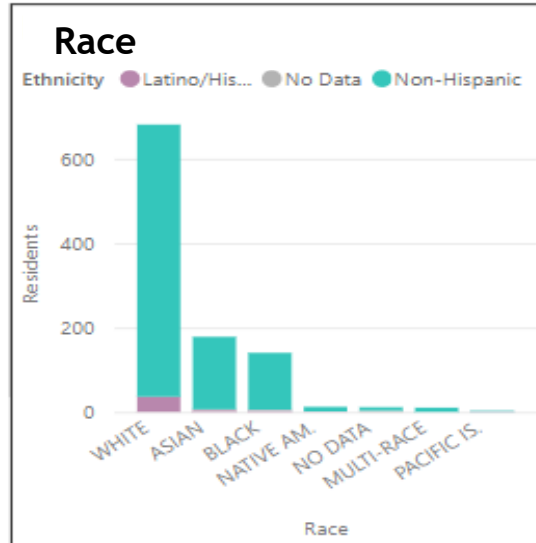
- 3 WHEN: 2020-2021
WHO: SHA Administration
WHAT: Contracts with Public Health Nurse with expertise in planning and research

- 4 WHEN: August 2021
WHO: SHA Administration
WHAT: SHA releases RFP, "Addressing High Clutter"

- 5 WHEN: 2022
WHO: FLC
WHAT: signs contract with SHA in June; starts work July 1.

Seattle Housing Authority (SHA)

Seattle Senior Housing Portfolio Demographic Data



Mean age: 74.65 (n=1035)

How many people have hoarding disorder?

A systematic review and meta-analysis showed a **2.5% prevalence**, with similar rates for males and females (Postlethwaite, 2019).

The rate is significantly greater for older adults - **6.2%** (Roane et al, 2017)



What is Hoarding Disorder?

The DSM-5-TR definition for hoarding disorder includes:



1. Persistent difficulty discarding items or parting with possessions regardless of their actual value
2. Difficulty is due to a perceived need to save items and distress with discarding them
3. Living spaces cannot be used for their intended purposes due to clutter
4. Causes significant distress or impairment

(APA, 2022; Springer, Worden, Tolin, 2019))

Hoarding Disorder is not...

...just a messy desk or bedroom!



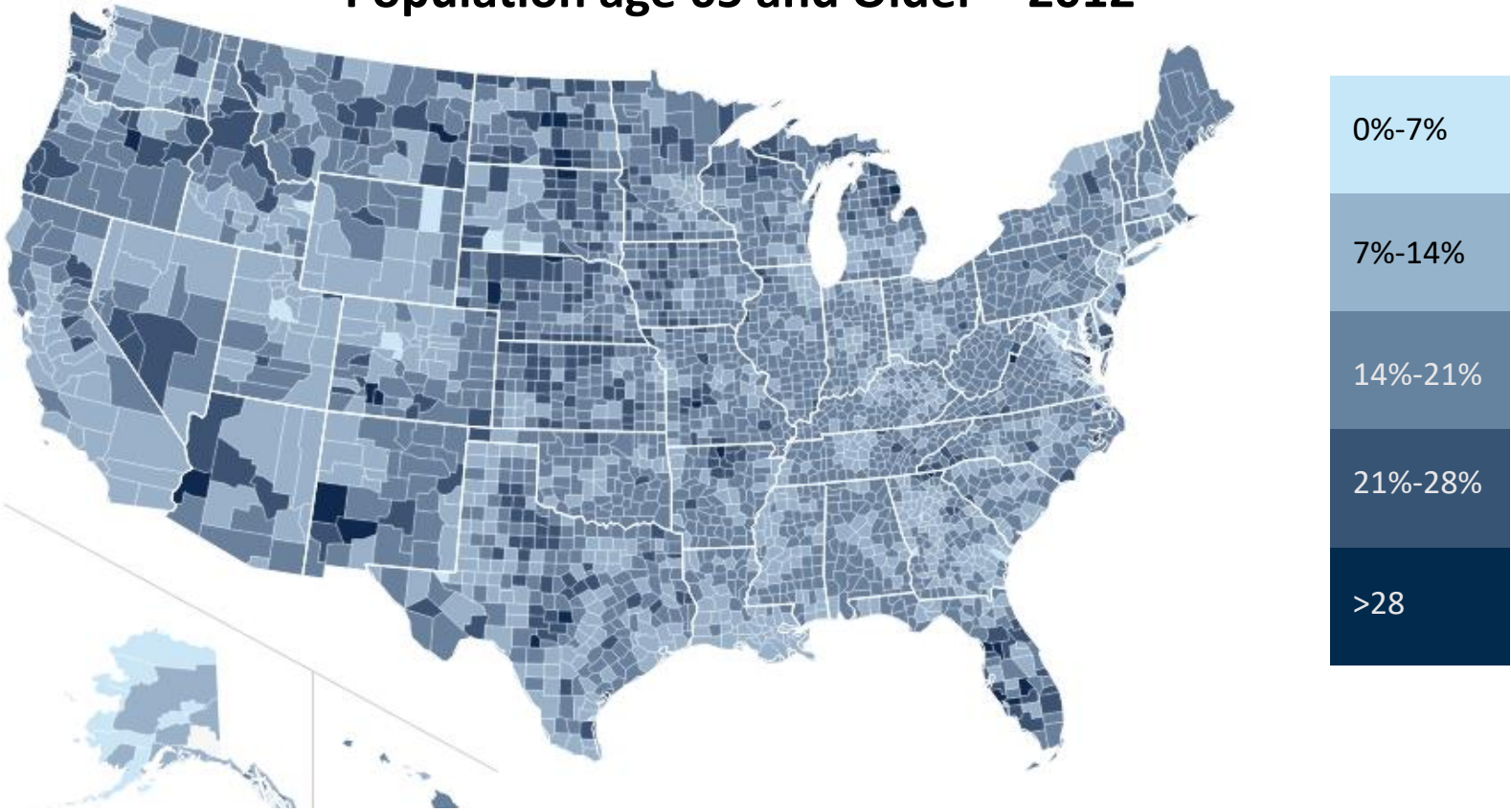




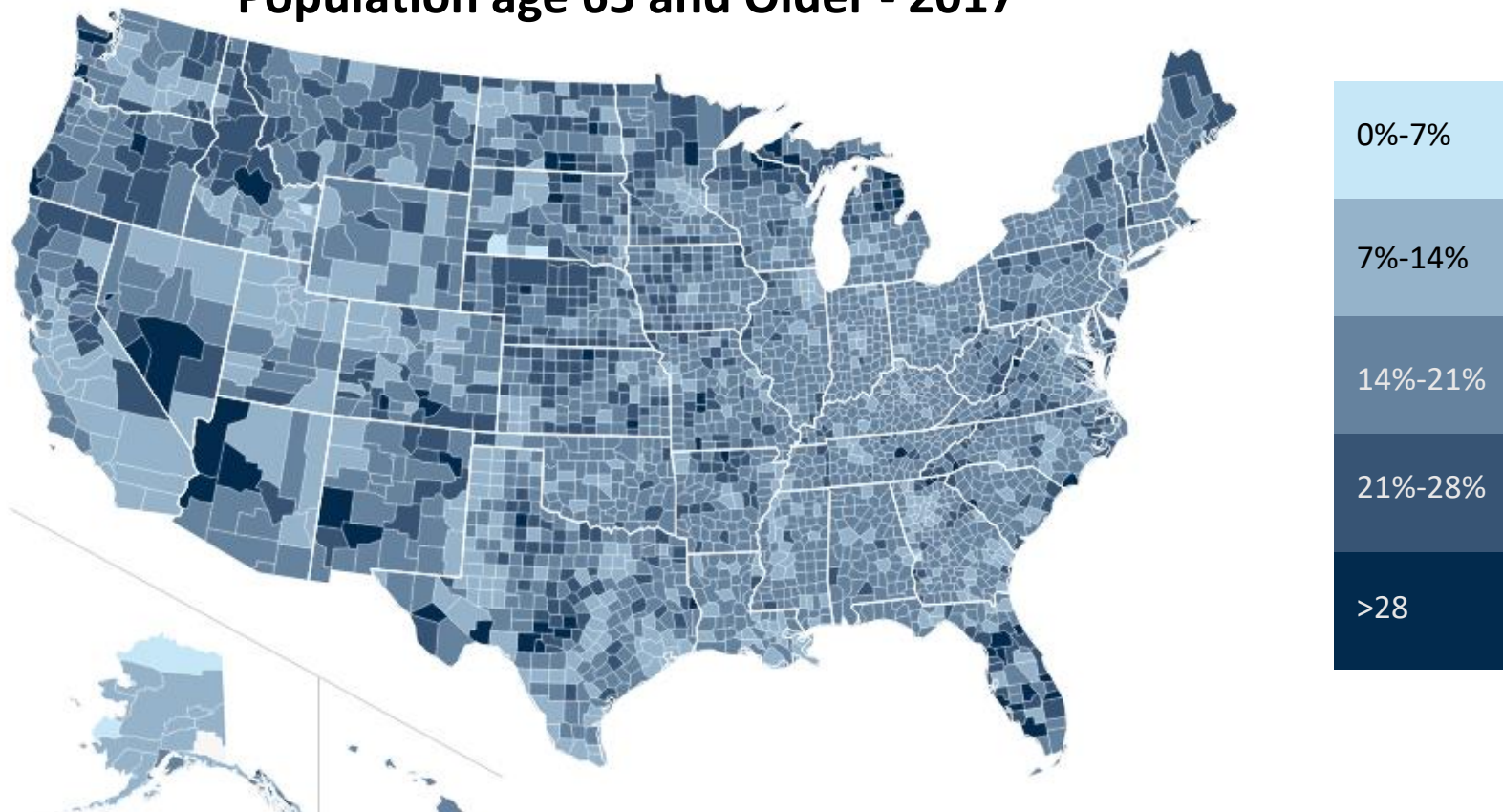




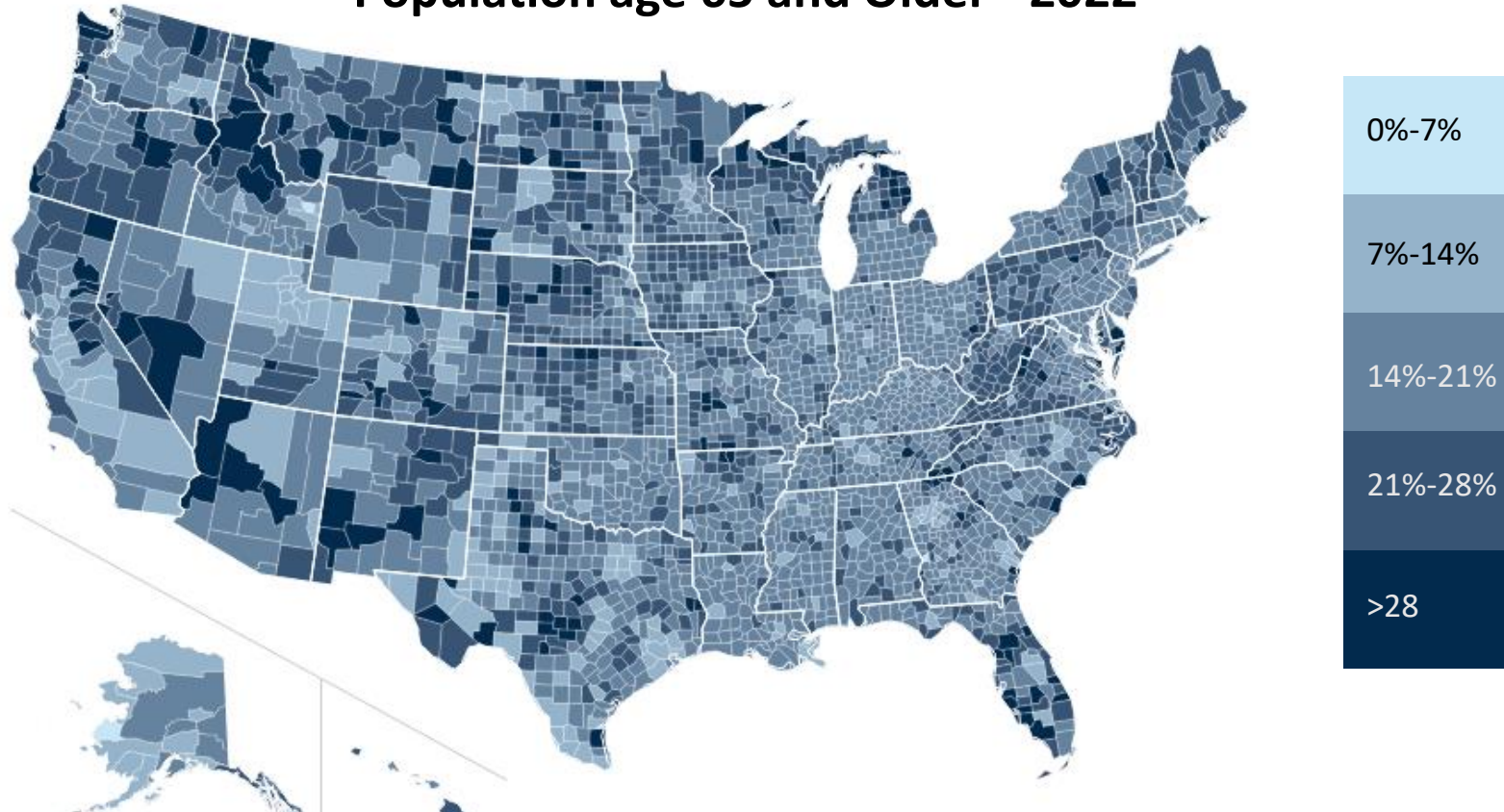
Population age 65 and Older – 2012



Population age 65 and Older - 2017



Population age 65 and Older - 2022



Aging in Place



- ▶ Many older adults want to "age in place" — stay in their own homes as they get older — but may have safety concerns, concerns getting around, or other issues performing their daily activities.
- ▶ Aging in Place is disrupted by the health and safety issues related to hoarding disorder, and home and life hygiene.

(Aging in Place, n.d.)

Addressing Clutter and Hoarding Program (ACHP)

CREST

Cognitive Rehabilitation & Exposure/Sorting Therapy

Elements of the program:



Evidence-Based program for treating hoarding disorder in older adults



26 weeks



Cognitive Rehabilitation



Exposure Therapy

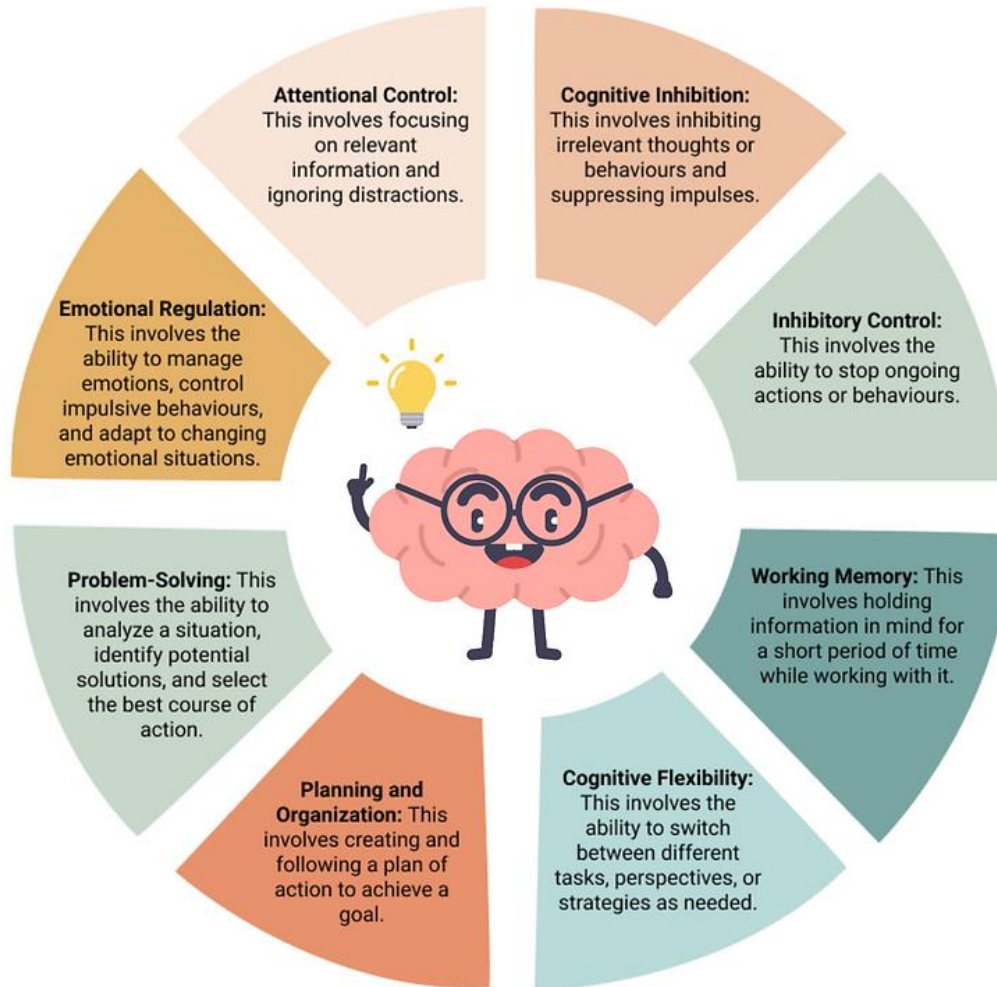


Case Management



Aftercare

Mind Your Executive Functions



(Ayers et al, 2018; Ayers, Najmi, Mayes, & Dozier, 2015; OT & Me, 2023)

CREST

Cognitive Rehabilitation

- ▶ Definition
 - ▶ A structured set of therapeutic activities designed to retrain an individual's ability to think, use judgment, and make decisions.
 - ▶ The focus is on improving deficits in memory, attention, perception, learning, planning, and judgment.
- ▶ Example:
 - ▶ Cognitive Flexibility
 - ▶ Cognitive Flexibility involves switching between tasks, perspectives, or strategies as needed.
 - ▶ What are some ways to use a toy hoop?



(Ayers et al, 2018; Ayers, Najmi, Mayes, & Dozier, 2015; Giles et al, 2019)

CREST

Exposure Therapy

- ▶ Definition
 - ▶ An evidence-based approach to confronting fears/avoidances safely and systematically.
- ▶ Example:
 - ▶ Alice is terrified of spiders and goes out of her way to avoid them. Guided by her therapist, Alice views a photo of a spider and watches a spider documentary. Alice later agrees to touch a spider her therapist brings into the session, eventually allowing the spider to walk over her bare arms.



▶ Alice's Fear Hierarchy

100	Let a large spider walk on arms
90	Sit next to a spider in a terrarium
85	Hike a trail where spiders are common Stand
80	5 feet from a spider in a web
70	Watch a long documentary about spiders
65	Watch a short video clip of a spider
60	Look at a photo of a tarantula

(Ayers et al, 2018; Ayers, Najmi, Mayes, & Dozier, 2015)

Occupation-based Interventions

- ▶ Occupations are activities one engages in during daily life - what people spend their time and energy doing.
- ▶ Occupation-based interventions are interventions that involve active participation in daily activities.
- ▶ Focuses on improving peoples' occupations, not solely on the underlying factors
- ▶ Participant-centered
- ▶ Collaborative/partnership in care



(Psillias & Stav, 2021; Spear, 2014)

Occupation-based Interventions

▶ Examples:

- ▶ Facilitating community reintegration by practicing real-life activities such as taking public transportation, grocery shopping, or attending social events.
- ▶ Engaging in hobbies and leisure activities such as painting, playing a musical instrument, or birdwatching.
- ▶ Supporting cooking and meal preparation such as chopping vegetables, following recipes, and using kitchen appliances.
- ▶ Establishing daily routines and habits such as setting wake-up times, planning activities, and managing household chores.
- ▶ Decluttering, organizing, and creating functional spaces.
- ▶ Assessing home hazards and providing safety education.
- ▶ Addressing fall prevention, fire safety, and emergency evacuation plans.



(Clarke, 2019; Dissanayake, Barnard, & Willis, 2017; Psillias & Stav, 2021; Spear, 2014)



Takeaway Strategies

How can I help?

- ▶ **Listen!**
- ▶ Match the person's language
- ▶ Avoid making suggestions about the person's belongings:
 - ▶ Table the judgment!
- ▶ Avoid touching objects in the home. If it is necessary, ask for permission
- ▶ Avoid focusing on the removal of items
- ▶ Help identify a vision for what future life might be like
 - ▶ Child to visit? Grandchild?
 - ▶ Space to make art?
 - ▶ Better health?
- ▶ Encourage connection to behavioral or mental health services

Questions?



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Other Resources

Books and Publications:

1. *Buried in Treasures: Help for Compulsive Acquiring, Saving, and Hoarding* by David F. Tolin, Randy O. Frost, and Gail Steketee.
2. *Stuff: Compulsive Hoarding and the Meaning of Things* by Randy O. Frost and Gail Steketee.
3. *The Hoarding Handbook: A Guide for Human Service Professionals* by Christiana Bratiotis, Cristina Sorrentino Schmalisch, and Gail Steketee.

Websites and Organizations:

1. **International OCD Foundation (IOCDF):** Provides information, resources, and support for individuals with obsessive-compulsive disorder (OCD) and related disorders, including hoarding.
2. **Children of Hoarders:** A community and resource for individuals who grew up in hoarding households.
3. **National Association of Professional Organizers (NAPO):** Offers professional organizing services and resources for decluttering and organizing spaces.
4. **Center for Hoarding and Cluttering:** <https://www.centerforhoardingandcluttering.com/>

Support Groups and Therapists:

1. **Local Support Groups:** Check community centers, mental health clinics, or online platforms for local hoarding support groups.
2. **Licensed Therapists:** Seek therapists specializing in hoarding disorder or cognitive-behavioral therapy (CBT).

Hoarding Task Forces & Other Information: <https://hoarding.iocdf.org/hoarding-task-forces/>

U.S. Senate Special Committee on Aging Request for Information:

https://www.aging.senate.gov/imo/media/doc/hoarding_disorder_rfi_-_senate_aging_committee.pdf

Thank you!



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