

**“Can you imagine your dad telling you:**

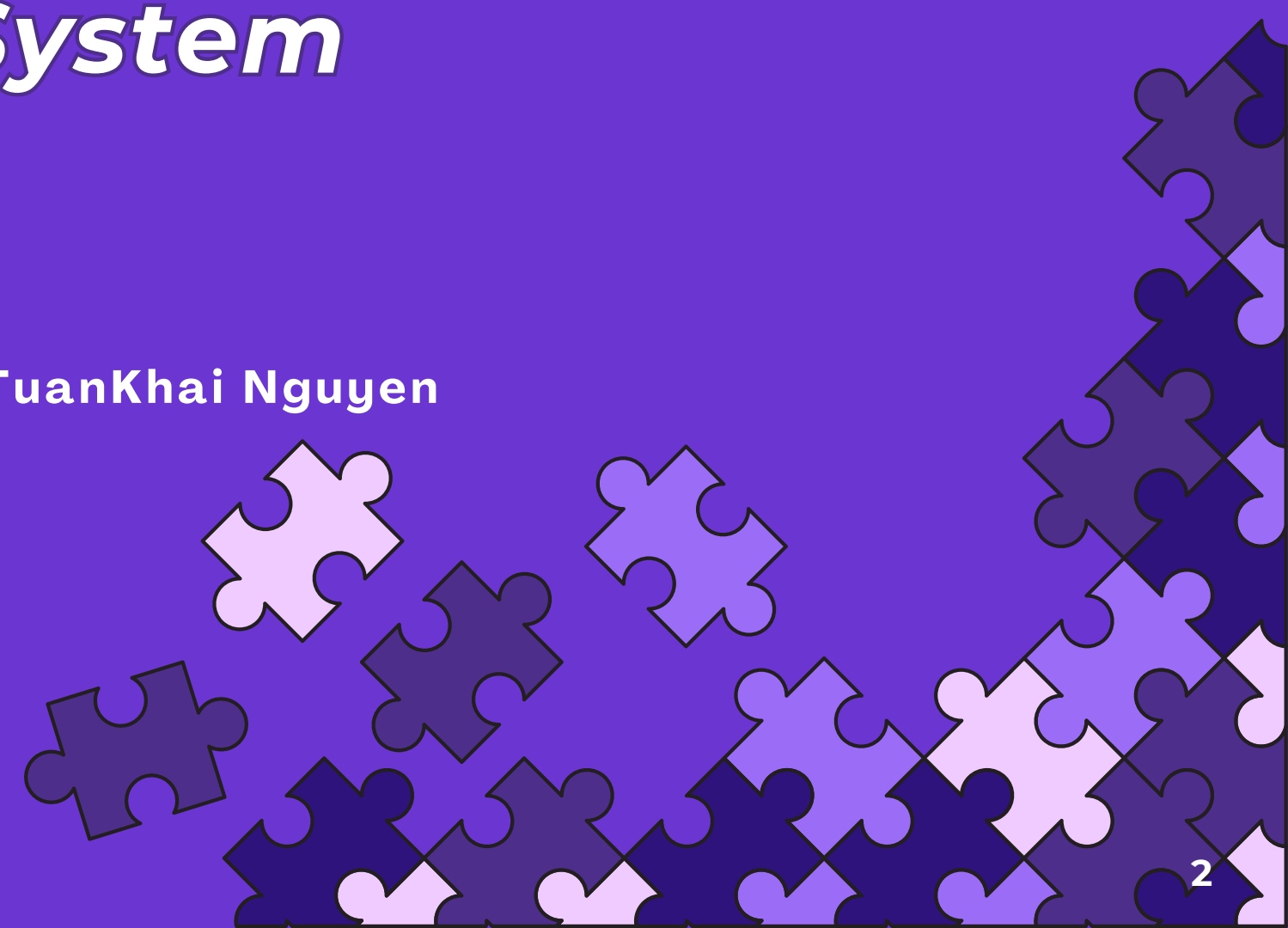
**“ I never loved you, I wish you were never born.”**

**Then he woke up cheerfully the next day,  
not remembering anything?”**



**BEYOND MEMORY LOSS:**  
*Disparities in the United States*  
*Alzheimer's Care System*

Eliam Chang, Heeba Momen,  
Somaiya Monowar, Yuxuan Raney Yang, and TuanKhai Nguyen



# Motivation

**“It affects us emotionally as well because seeing your parents digress like this is really hard, and there is nothing you can do about it, so yes it causes depression, it causes anxiety, it causes emotional sadness.”**



- Tonya Brown  
(Daughter of Alzheimer's Patients)

# People Interviewed



**Darin Gordon**  
Director of Tennessee's Medicaid program  
TennCare



**Susan Yenke**  
Daughter of Alzheimer's Patient  
Vanderbilt University



**Brett A. Parker, MD**  
Neurologist  
Ascension Medical Group



**Nicolette Wise, MPH, CHES**  
Social Determinants of Health Director  
TennCare



**Tonya Brown**  
Caregiver of Alzheimer's Patient  
the Wond'ry



**Jingqiong Kang (Katty), MD, PhD**  
Associate Professor of Neurology  
Vanderbilt University Medical Center



**Tiffany Cloud-Mann, M.Ed.**  
Eldercare Coach & Community  
Partnerships Manager  
Agewell Middle TN



**Dawne Bunn**  
Regional Leader - TN, AL, MS, and LA  
Alzheimer's Association®



**Elisabeth Dykens, PhD**  
Professor of Psychology and  
Human Development  
Vanderbilt Kennedy Center



**Alexander Heaton, MA**  
Former Policy Advisor for Public Safety  
Office of the Mayor at the City of Chicago

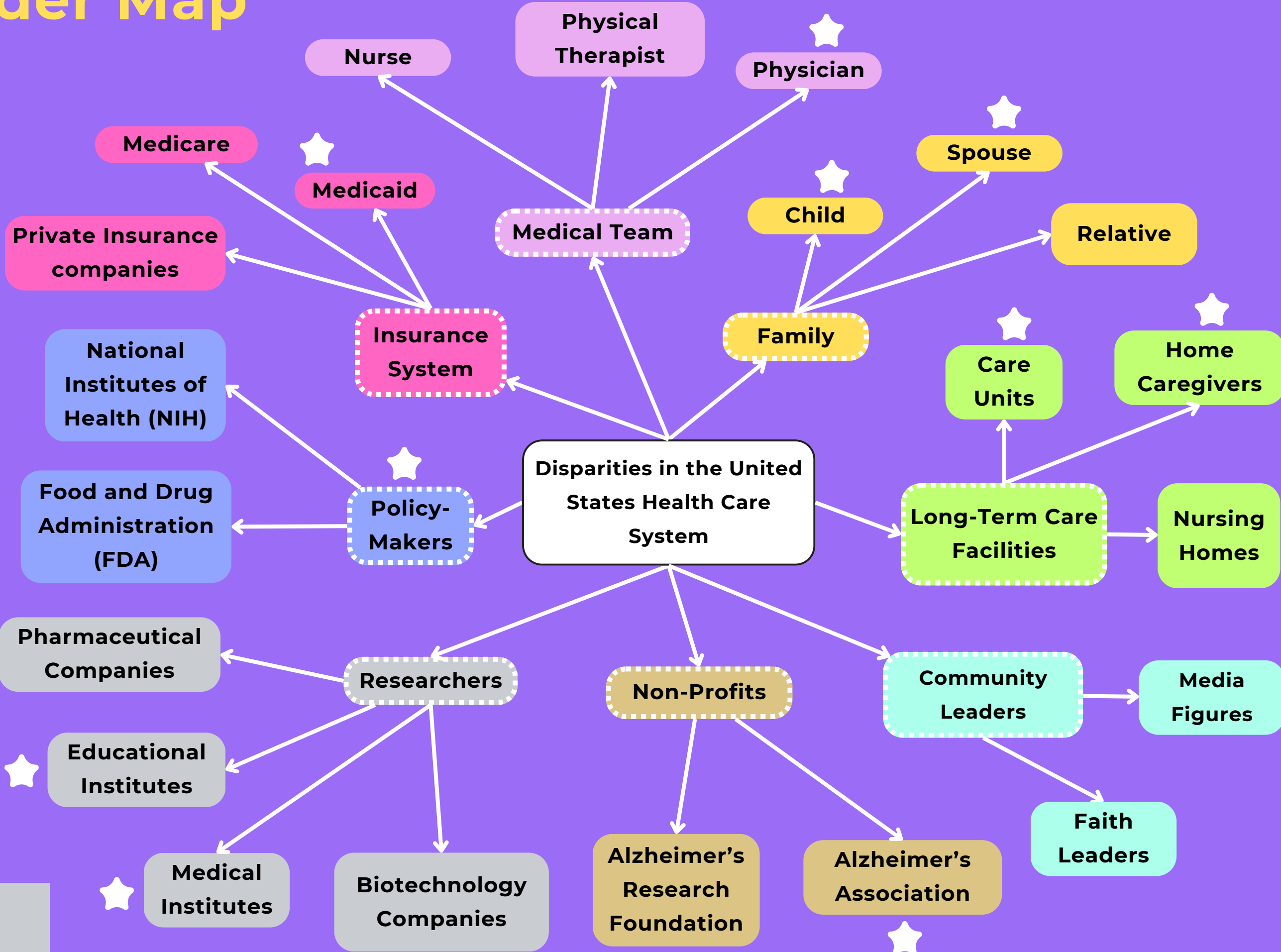


**Mary Kate Schroeter, MSA**  
Humanitarian Advisor  
United States Agency for  
International Development  
(USAID)



**Mary Ellen Koran, MD, PhD**  
Assistant Professor of Clinical  
Radiology & Radiological Sciences  
Vanderbilt Memory and  
Alzheimer's Center  
(seminar)

# Stakeholder Map



★ people interviewed

# Power-Interest Map

**Power** = ability to change the disparities within Alzheimer's

**Interest** = desire for change disparities within Alzheimer's

“We are not a Medicaid expansion state and that is largely a political decision that I have no power in.”



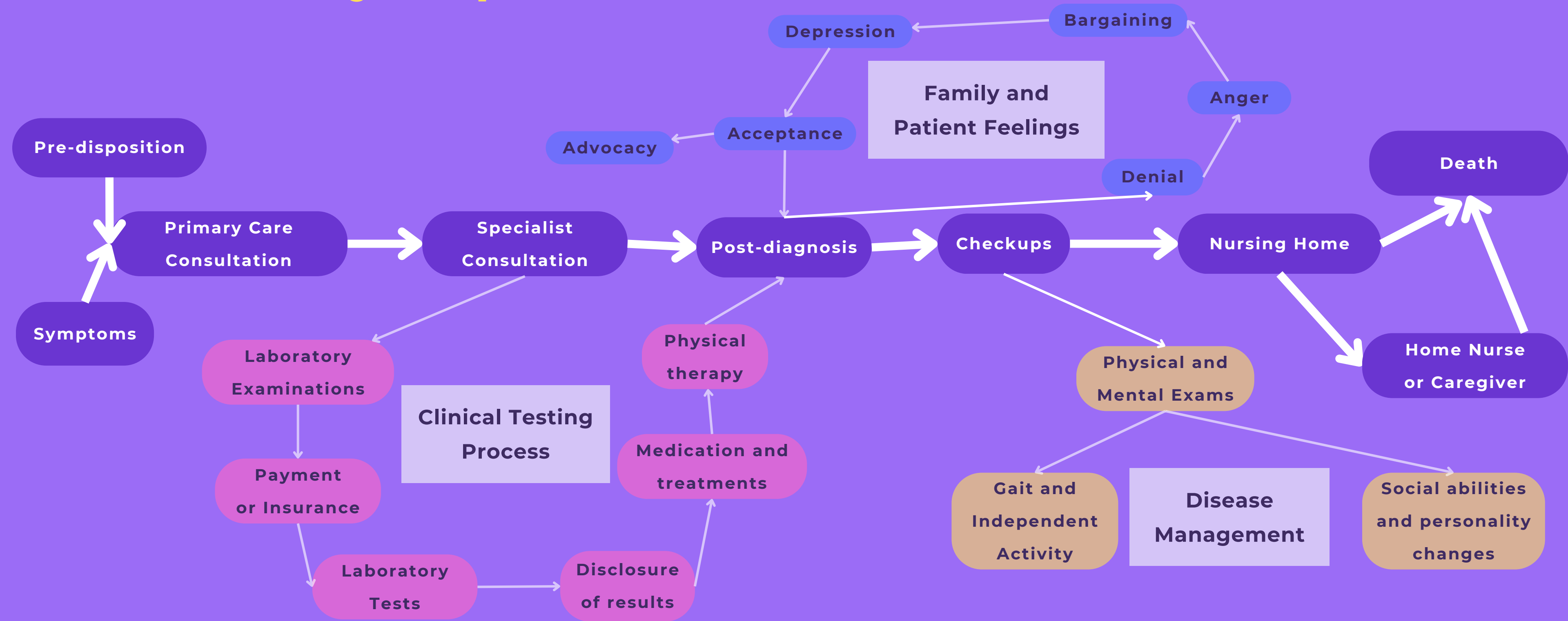
Nicolette Wise, MPH, CHES  
 Social Determinants of Health Director  
 TennCare



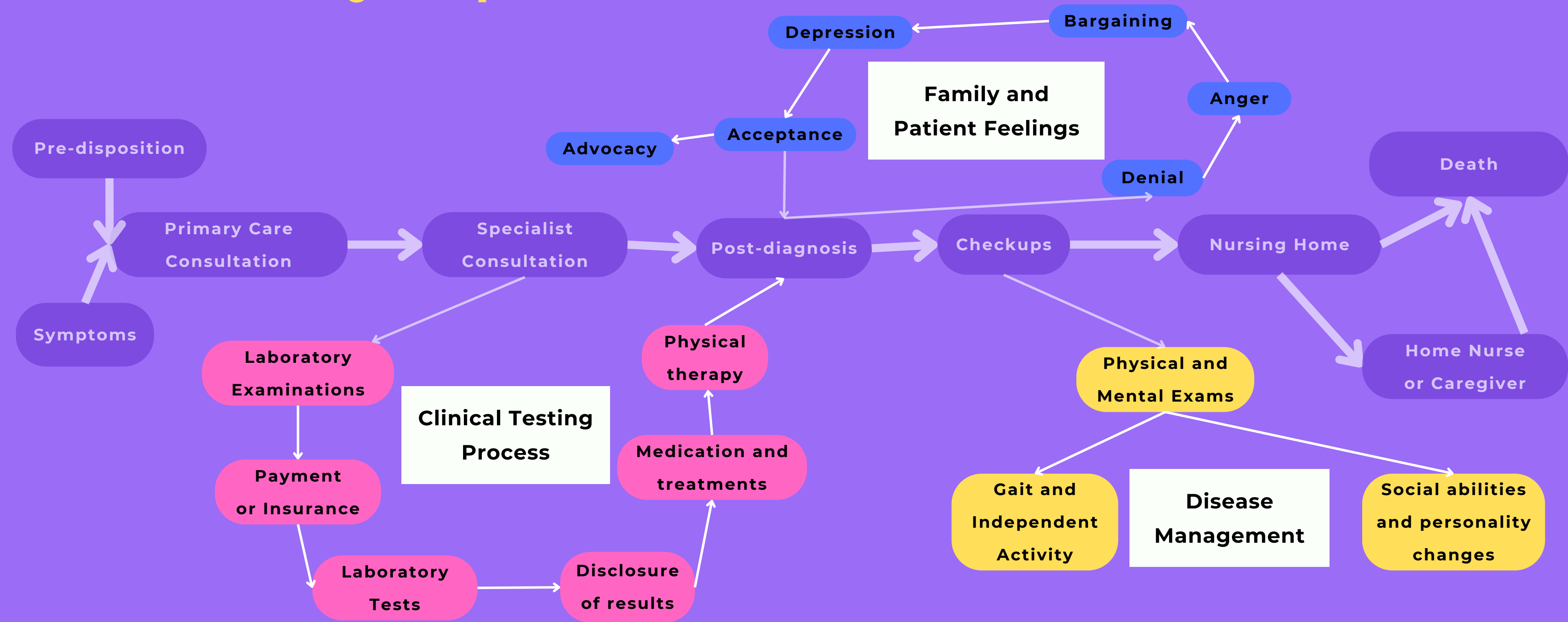
Low Interest

High Interest

# Journey Map

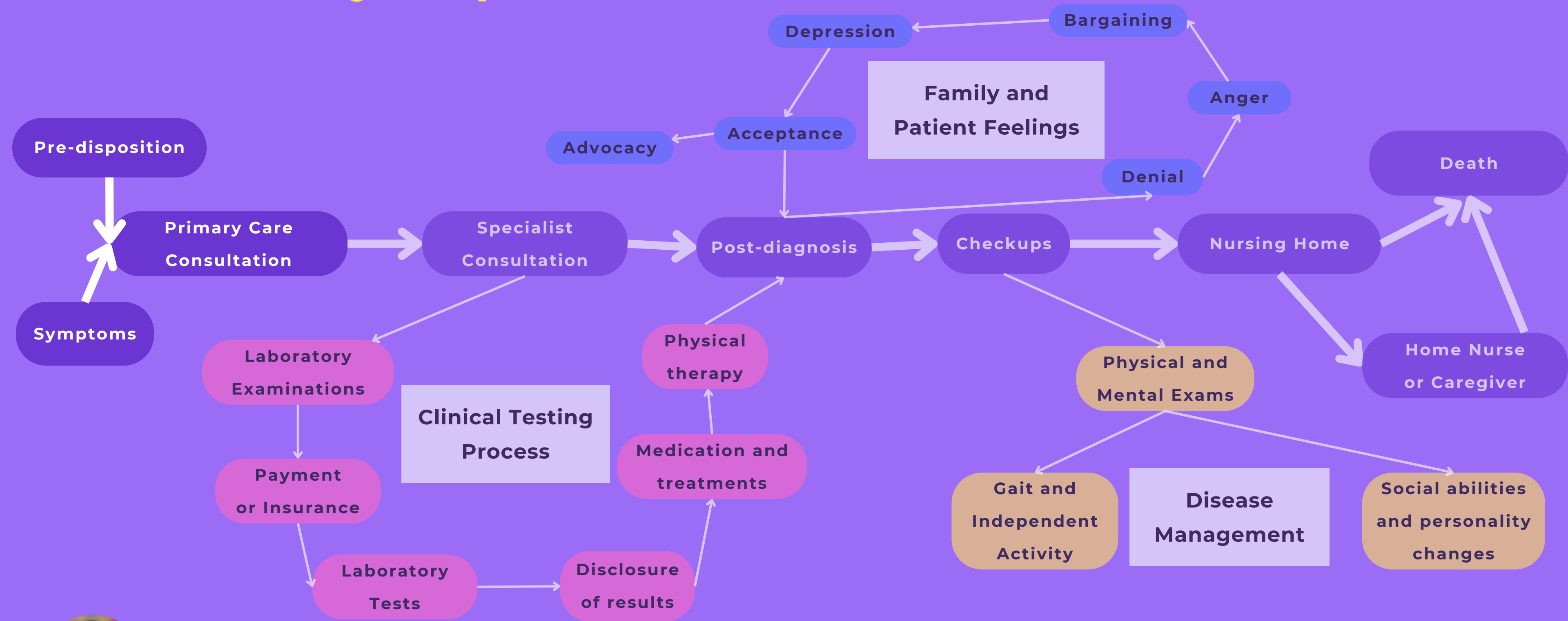


# Journey Map





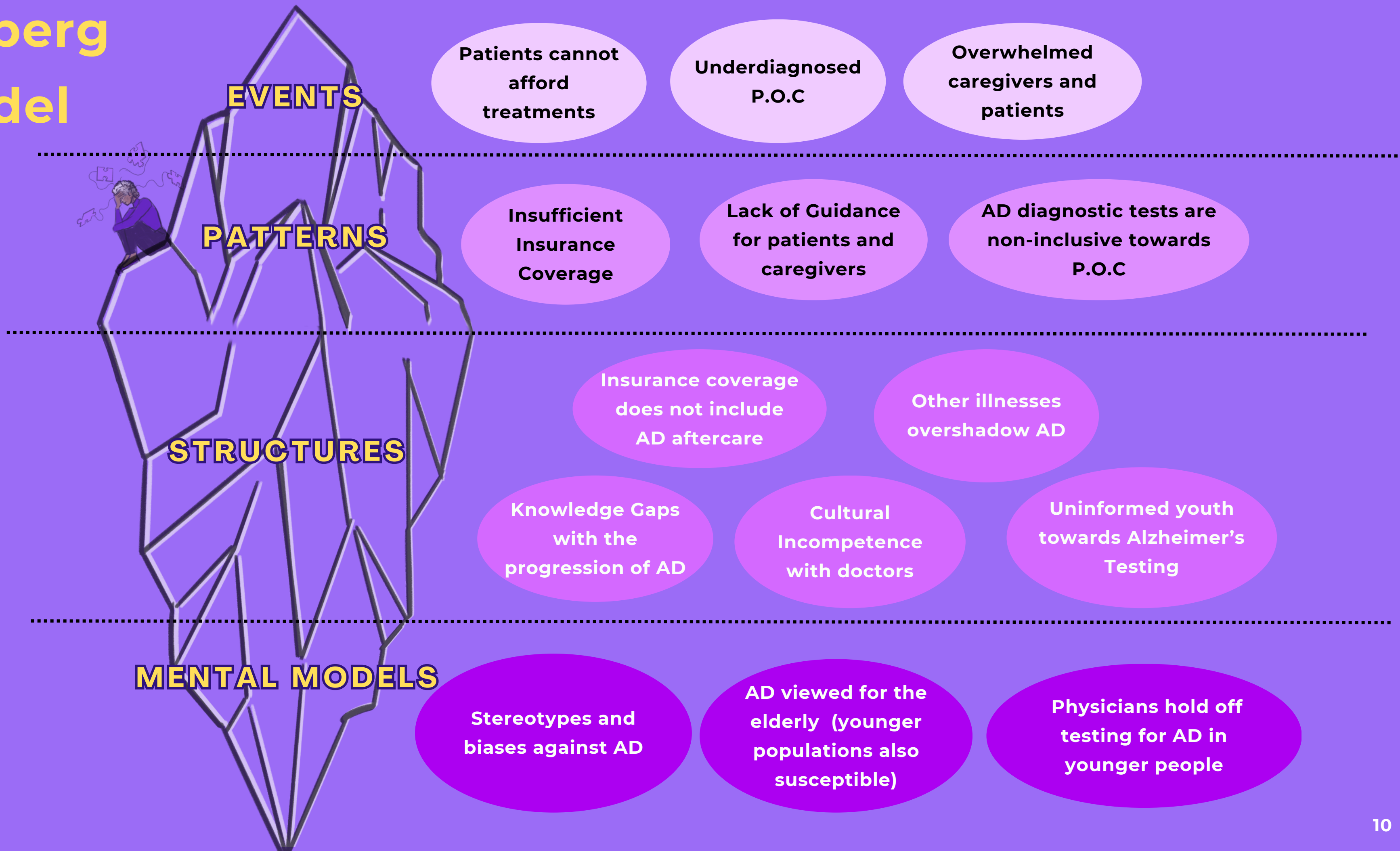
# Journey Map

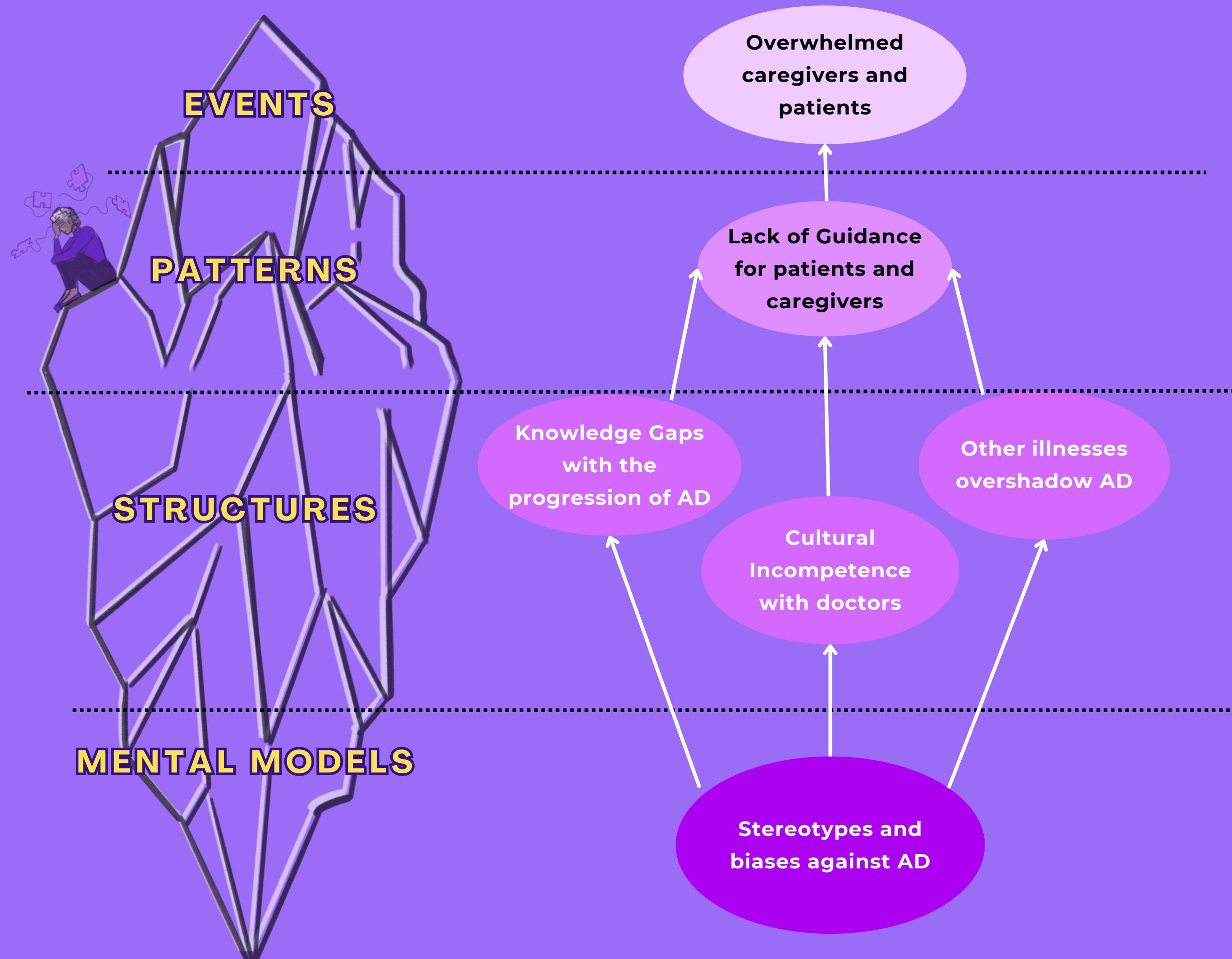


Susan Yenke  
 Daughter of Alzheimer's Patient  
 Vanderbilt University

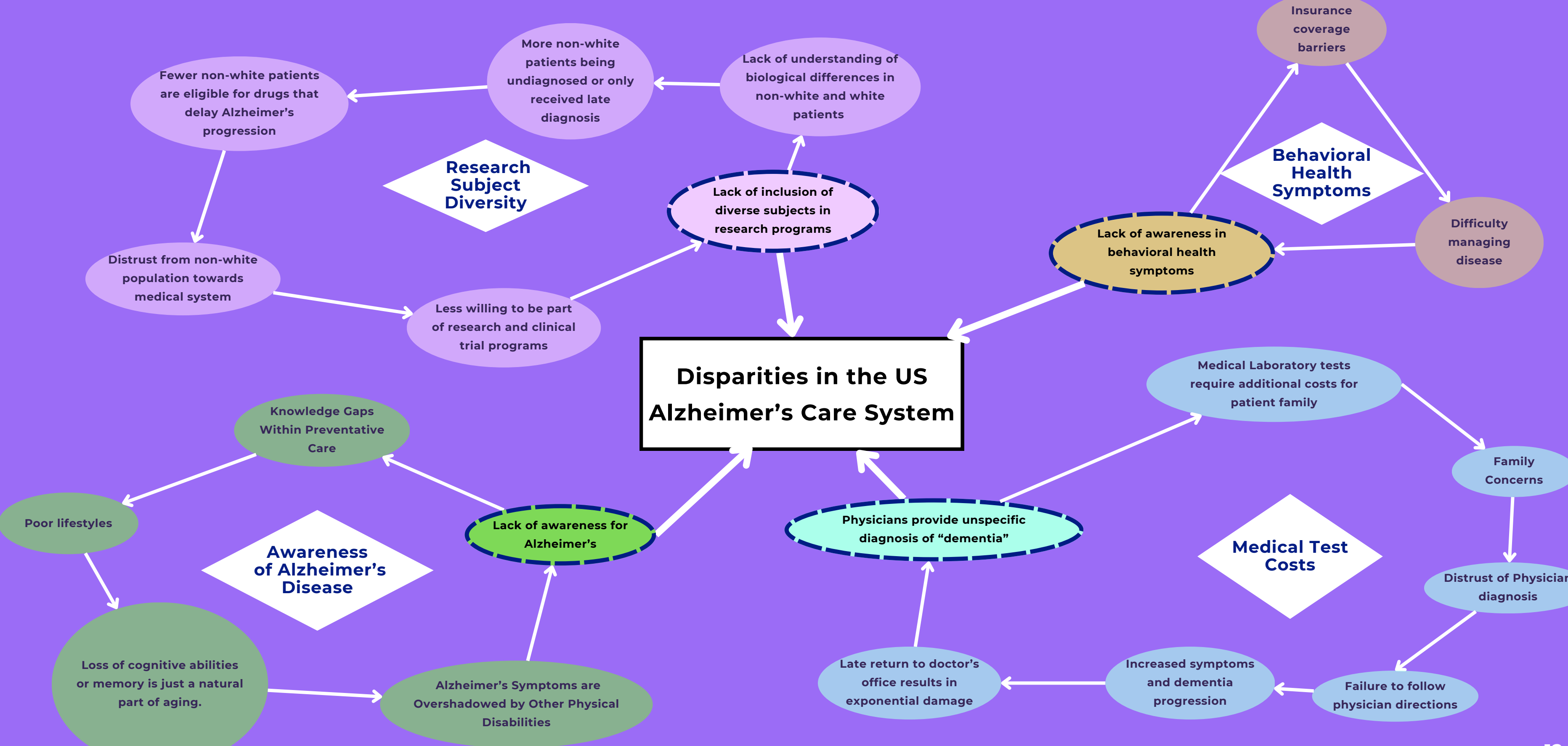
“Often, the patient doesn’t know what is going on. It takes a third party to get to the diagnosis.”

# Iceberg Model

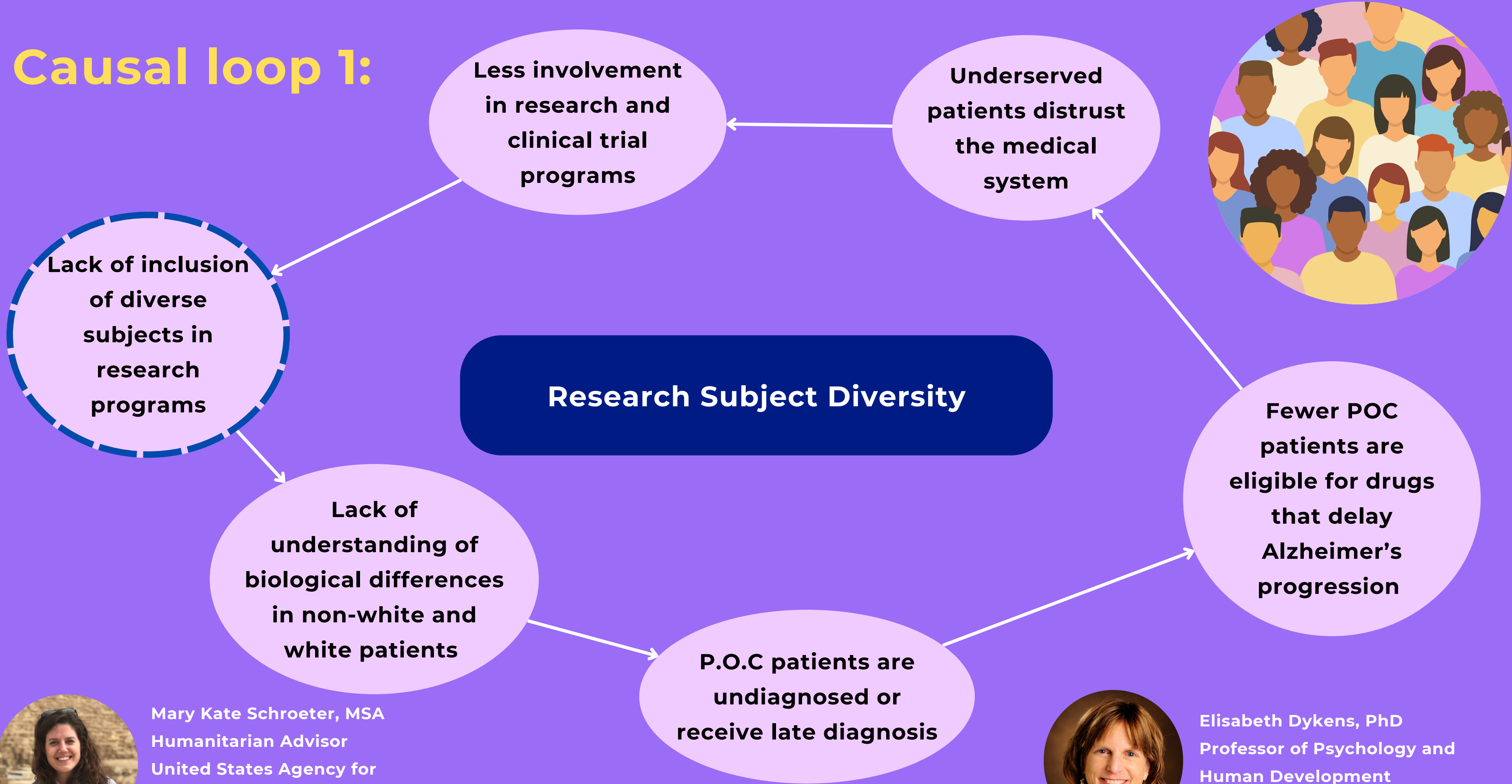




# Problem Factors as Causal loops



# Causal loop 1:

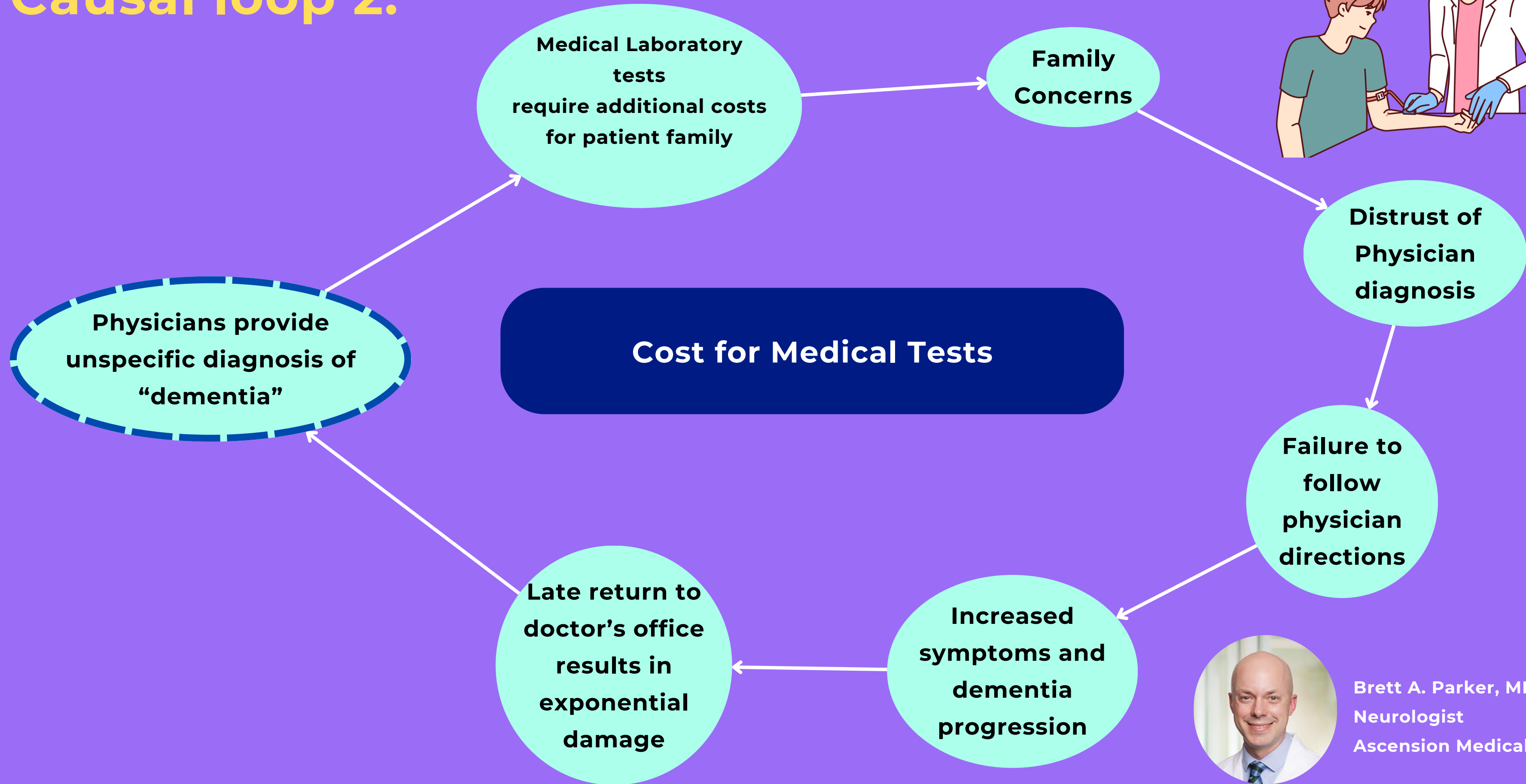


Mary Kate Schroeter, MSA  
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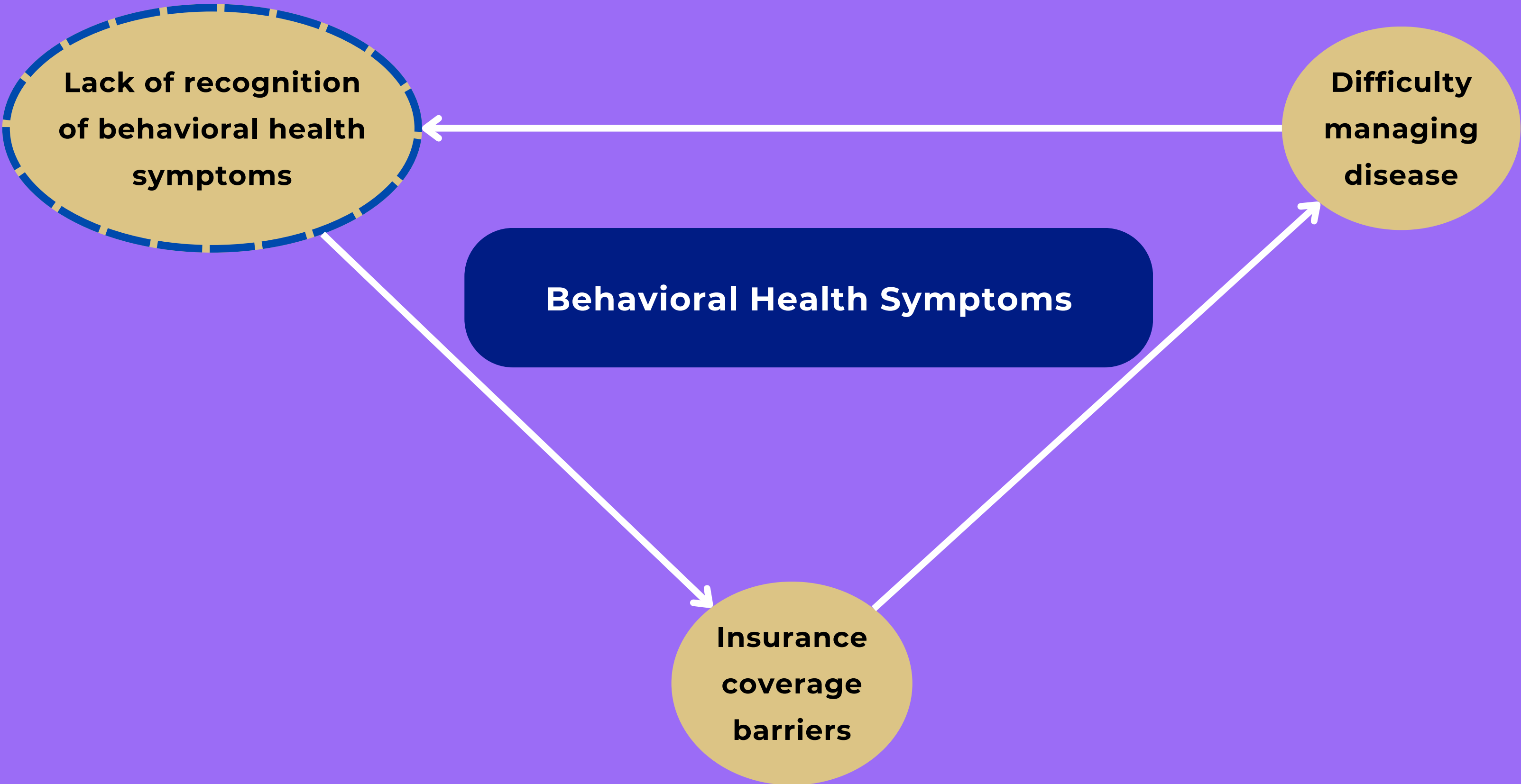
Elisabeth Dykens, PhD  
Professor of Psychology and  
Human Development  
Vanderbilt Kennedy Center

# Causal loop 2:

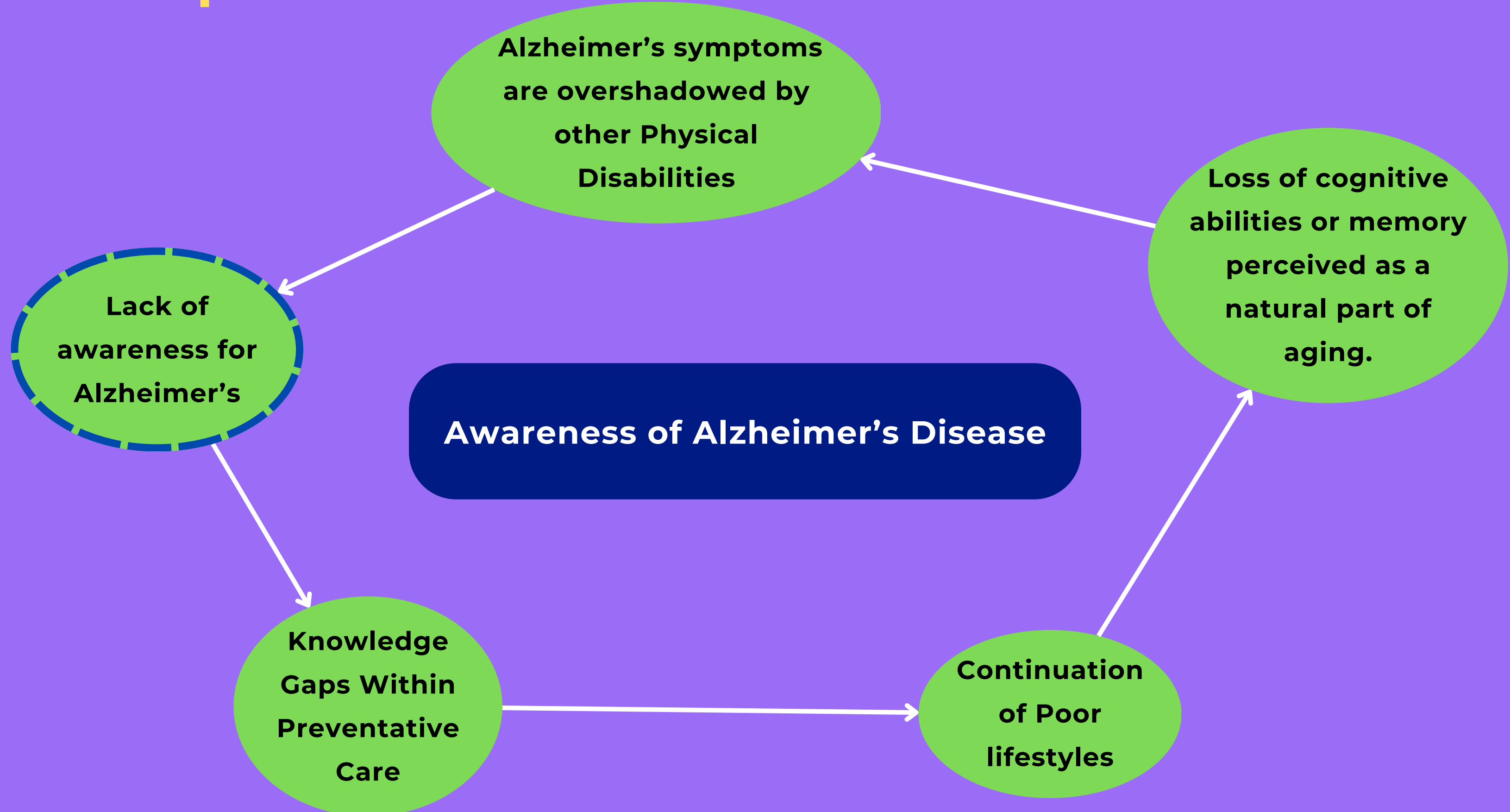


Brett A. Parker, MD  
Neurologist  
Ascension Medical Group

# Causal loop 3:



# Causal loop 4:





# Levers of Change

-Medicare only covers behavioral specialist visits-

Gap	Levers	Change
<p>Patients <u>under</u> 65 qualify for Medicare but are not covered for <u>behavioral health medications</u>; they exhaust their resources and are left financially disadvantaged.</p>	<p>Significance of <u>behavioral</u> needs for patients <u>under</u> 65.</p>	<p>Adjust Medicare coverage for patients <u>under</u> 65 with Alzheimer's.</p>

Health Insurance Disparities

Clinical Research Disparities

Public Awareness Disparities





**-Diagnostic tests developed with mainly AD white patients-**

**Health  
Insurance  
Disparities  
Disparities**

**Clinical  
Research  
Disparities**

**Public  
Awareness  
Disparities**

**Gap**

**Different racial and ethnic groups receive healthcare differently.**

**Levers**

**Physicians and researchers diversity.**

**Clinical trials subject diversity.**

**Change**

**Prepare a competent workforce to care for culturally and racially diverse elderly population.**

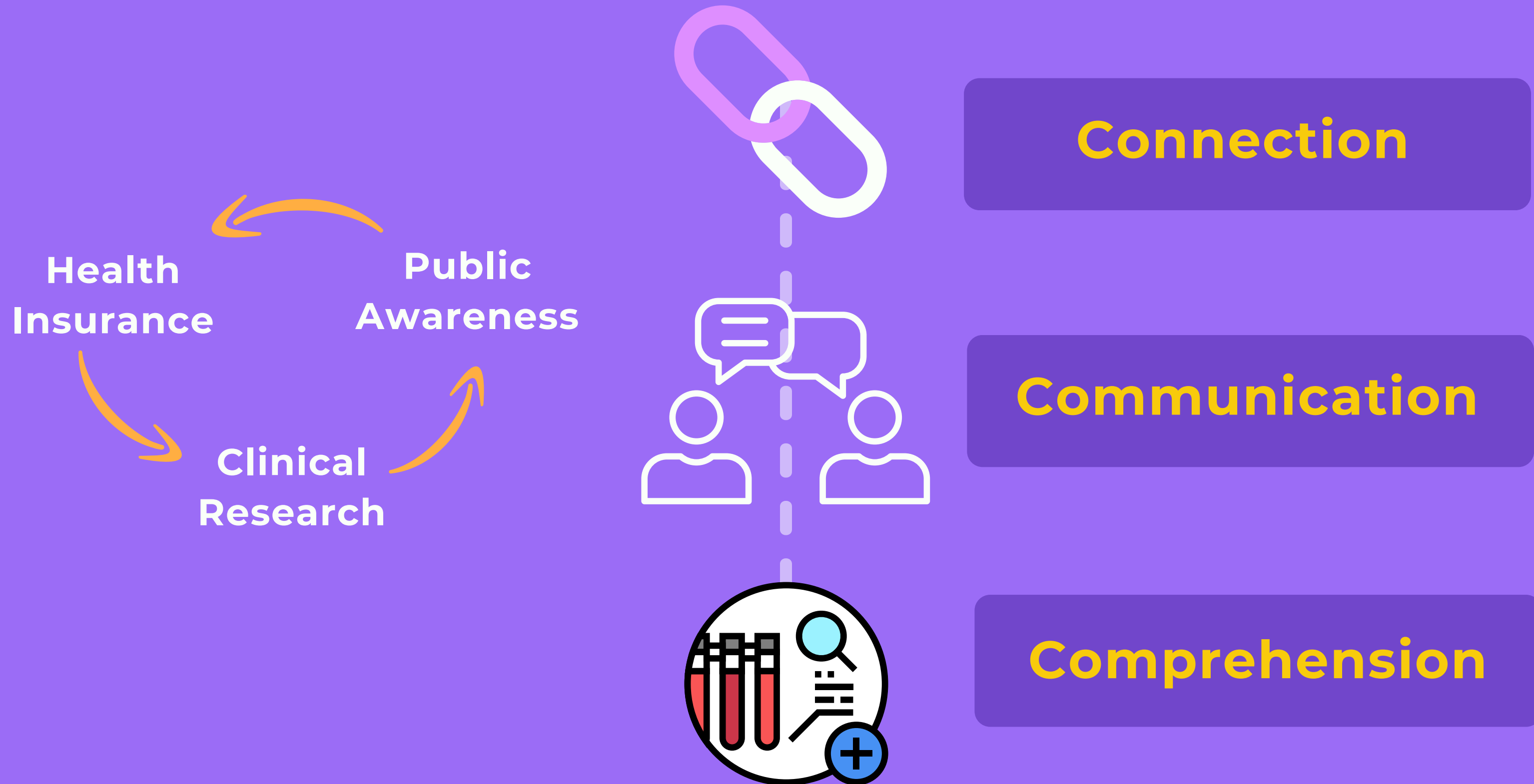
**Establish regulatory requirements to recruit and retain participants for diverse clinical trials.**

**-NGOs organize conventions, virtual support groups, and helplines-**

	Gap	Levers	Change
Health Insurance Disparities Disparities	<u>Distrust</u> in the medical system from historical context	<u>Shift cultural perspectives</u> of minority populations.	Establish <u>research outreach programs</u> to bridge knowledge gaps on Alzheimer's.
Clinical Research Disparities		Mobilize <u>government resources</u> to support underserved patients.	Identify community-specific <u>public figures</u> and collaborate with <u>NGOs</u> awareness programs.
Public Awareness Disparities			Establish <u>disease advocacy alliance</u> across geographical (urban/rural) communities.



# Key Insights and Lessons Learned



# Conclusion

**People deserve the courage  
and knowledge to live  
Beyond Alzheimers, and  
Beyond Memory Loss.**



# Acknowledgements



**Thank you for Listening!**

