Adopting and Aging and Disability Perspective to Identify National Computing Research Priorities:

Implications for Learning Health Systems and Recommendations from the PCAST Report on Technology

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Presentation Objectives

- **Part 1**: **Communicate** Dr. Christine Cassel's slides in the context of the recent PCAST Report on "Independence, Technology, and Connection in Older Age."

- **Part 2: Illustrate** the intersection of the aging and disability experience and highlight shared needs and opportunities for technology based interventions and services.

- **Part 3: Describe** the key priorities of serving older adults and persons with disabilities (i.e., accessibility, usability and person-centered planning), and their implications for the learning health systems concept and for shaping an inclusive computing research agenda that is responsive to the needs of both target populations.

PART 1:
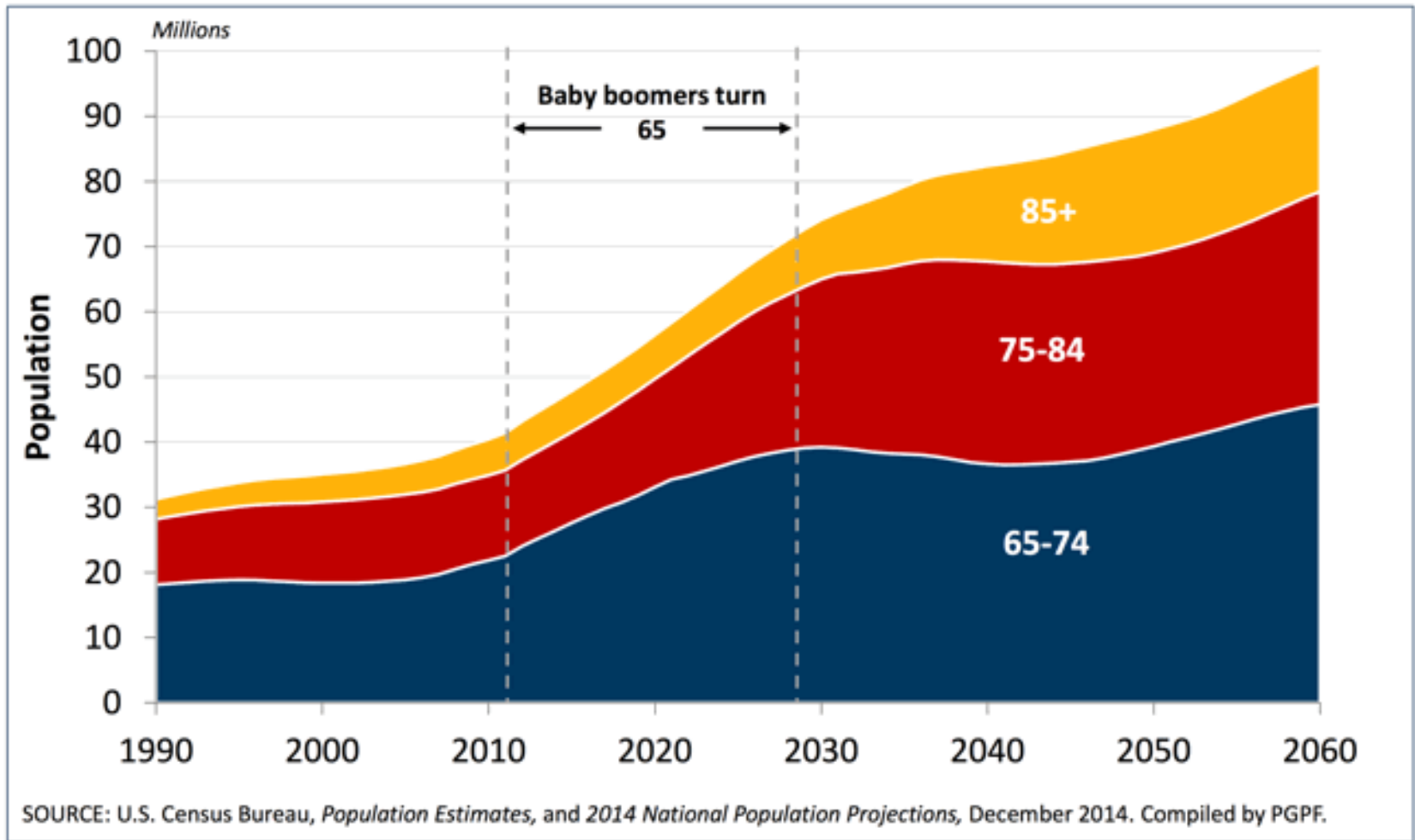# Chris Cassel's Slides & Recommendations from the PCAST Report

Systems Engineering: Complexity and Personalization are Key to Good Geriatric Care

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May 9, 2016

Americans Living Longer

SOURCE: U.S. Census Bureau, *Population Estimates*, and *2014 National Population Projections*, December 2014. Compiled by PGPF.

Characteristics of Aging Population

- Heterogeneous
- Multiple conditions
- Multiple medications
- Risks of hospitalization
- Multiple providers

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Goals of Systems Engineering

- Coordination
- Avoiding gaps
- Reduced duplication
- Avoiding errors
- Patient-centered

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What We Need from Data and Analytics

- Comprehensive patient-centered data

- Complete interoperability and data fluidity

- Community sources combined with health care sources

- Patient and family access to information technology

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Primary Focus Areas of the PCAST Report

- Key Changes Older Americans Often Experience with Aging:
  - Hearing Loss
  - Loss of social engagement and connectivity
  - Cognitive Change
  - Physical Change

PCAST Technology-Related Recommendations to Address Aging Changes/Challenges

- **Cross-Cutting:**
  1. **Integrating Federal Action** -- to identify technologies vital to aging and advise on sector-wide ways to advance technology (key agencies: OSTP/ NCST, NSF, HHS).
  2. **Engagement and Social Connectivity** – Establish a national plan to ensure access to Internet communications, which are essential to health, social engagement, and well-being (HHS/ACL, NTIA, DOC, FCC)
  3. **Monitoring Technology for Frail and Vulnerable Elders (NIST)**
  4. **Federal Investments in Research to Spur Innovation --** Support Interdisciplinary and translational research including robotics, advanced mobility technologies, communication technology, with special emphasis on cognitive training, home monitoring, and improving regulatory and payment systems and home and product design (NIH, HHS Agency for Healthcare Research & Quality, NSF, VHA, DOD, DARPA).

PART 2:

The Intersection of the Aging and Disability Experience:
Shared Needs, Opportunities for Technology Tools and Products

Intersection of Aging and Disability Statistics

- **Aging:** About one in every seven, or 14.1%, of the U.S. population, is an older American.[1]

- **Disability:** The American Community Survey (ACS) estimates that in 2014 nearly 1 in 8 persons, or 12.6% of the U.S. population, had a disability. [2]

- **Aging & Disability**: Of the U.S. population with disabilities in 2014, 51.6% were people of working age (18-64) and 40.7% were people 65 and over. [2]

- **Aging & Disability**: Of the six ACS disability items, ambulatory difficulty was the most frequently cited, with the percentage increasing with age from 5.2% for 18-64 year olds to 23% of persons 65 and over. [3]

Aging "with" and "into" Disability Diagnoses and Chronic Conditions

Aging "*with*" disabilities
- Spinal cord injury
- Traumatic brain injury
- Neuromuscular disease
- Multiple sclerosis
- Developmental disabilities
- Post-polio syndrome

Aging "*into*" disabilities
-- Osteoarthritis
-- COPD
-- Vascular dementia
-- Coronary artery disease
-- Osteoporosis
-- Diabetes (complications)
    limb loss
    peripheral neuropathies

Aging & Disability Shared Risks & Needs for Technology

Shared Health Risks:

-- Risk of falls

-- Chronic pain

-- Risk for infections

-- Need for caregiver support

-- Cognitive impairment

-- Depression/withdrawal

-- Changes in vision/hearing

-- Mobility limitations

Shared Needs for Technology

-- Access to accessible and usable assistive and advanced technology devices and systems to support shared goals.

Aging & Disability: Shared Goals and Opportunities for Technology

- Promote Healthy aging
- Sustain/maximize function and independence
- Support Community Living
- Facilitate social and productive engagement

PART 3:

Key Priorities for Serving for Older Adults and PWD:
Implications for the Expanding the Concept of LHS and Shaping an Inclusive Computing Research Agenda and Delivering on the Promise of Technology for All Americans

Key Priorities for Serving Older Adults & PWD: Accessibility & Usability

- **Accessibility** – refers to ensuring an equivalent user experience for people with disabilities of all ages. For example, it means that people with disabilities can *perceive, understand, navigate, and interact* with websites and IT tools and systems and participate without barriers (World Wide Web Consortium [W3C]).

- **Usability** – refers to designing products to be *effective, efficient, and satisfying*. Usability is an aspect of human- computer interaction (HCI) research and design; and the practice of usability is largely about following a user-centered design (UCD) process to create positive user experiences (W3C).

Key Requirements for Serving Older Adults & PWD: Accessibility & Usability

- **Legislative and Regulatory Support for Accessibility**:
  - The Americans with Disabilities Act (ADA) and Section 508 apply to health IT, although they are not consistently enforced and have not been tested in the court system.
  - Section 1557 of the Affordable Care Act (ACA) prohibits discrimination based on disability.

- **Implementation Guidelines:**
  - The World Wide Web Consortium (W3C) offers free guidelines and tools that can enhance accessibility and interoperability (https://www.w3.org/WAI/).
  - Web Content Accessibility Guidelines (WCAG 2.0) to make the content of websites accessible (https://www.w3.org/WAI/intro/wcag).

Key Requirements for Serving Older Adults & PWD: Person-Centered Planning/Services

- **Definition**: A process that is directed by the person and identifies the strengths, preferences, service and support needs, and desired outcomes of the person, consistent with the person's health, cultural preferences, housing, family, employment, and social supports needs. [5]

- **Legislative and Policy Support:**
  - Affordable Care Act (ACA) Section 2402(a): Oversight and Assessment of the Administration of Home and Community Based Services
  - HHS Secretary's Guidance on Implementation of Section 2402(a) of the ACA
  - The Office of the National Coordinator for Health Information Technology (ONC) issued their 2015-2020 Strategic Plan and a National Interoperability Roadmap that provides a framework for health IT to empower individuals, families, and caregivers through improved health management and engagement. (https://www.healthit.gov/sites/default/files/federal-healthIT-strategic-plan-2014.pdf).

Implications of Aging & Disability Priorities for Learning Health Systems

- **Broaden** the definition of LHS beyond the healthcare system to:
  - Include the patient, family and/or caregiving system; and
  - Reflect bi-directional learning and engagement between providers and patients.
- **Expand** the model of LHS beyond the goal of "change in practice" to include "improved health and function outcomes" for older adults and people with disabilities (PwD).
- **Adop**t the priorities of "accessibility and usability" from disability and the values of "person-centered planning/services" from aging and disability to ensure that LHS and technologies are usable by and reflective of the needs of both target populations.

Implications of Aging & Disability Priorities for an Inclusive Computing Research Agenda

- **Elevate** "accessibility and usability" as a recognized national priority for of all new and emerging health information and other advanced technologies to ensure that these tools and systems are available to benefit all Americans.

- **Integrate** requirements for incorporation of accessibility and usability standards and guidelines into all federal funding initiatives.

- **Involve** stakeholders in the process of identifying national priorities for technology R&D to ensure that person-centered principles are followed.

- **Provide** researchers, developers, designers, and vendors with resources and training on accessibility standards and guidelines.

Implications of Aging & Disability Priorities for the PCAST Report Recommendations

- **Reduce federal silos** in technology R&D policy and funding initiatives by expanding the target population to include both older adults and individuals aging with disabilities.

- **Expand** federal involvement to include NIDILRR, the U.S. Access Board, and other disability regulatory and R&D agencies.

- **Incorporate** "accessibility and usability" as a priority in all cross-cutting and issue-specific recommendations.

- **Involve** disability researchers, developers, policy experts, and advocates in all federal and public-private task forces charged with identifying technologies vital to aging, developing a national research plan and educational and training materials, improving regulation and payment systems and product design standards, and shaping the future of assistive and robotic technologies.

Comments/Questions?

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Key References

1. *A Profile of Older Americans: 2014* was developed by the Administration on Aging (AoA), Administration for Community Living, U.S. Department of Health and Human Services. (Primary data sources are the U.S. Census Bureau, the National Center for Health Statistics, and the Bureau of Labor Statistics.)

2. Kraus, Lewis. (2015). 2015 Disability Statistics Annual Report. Durham, NH: University of New Hampshire. (Primary data source: U.S. Census Bureau: American Community Survey)

3. He, Wan and Luke J. Larsen, U.S. Census Bureau, American Community Survey Reports, ACS-29, *Older Americans With a Disability: 2008–2012*, U.S. Government Printing Office, Washington, DC, 2014.

4. Interagency Committee on Assistive Technology, Interagency Committee on Disability Research. Accessibility and Usability in Health Information Technology: A Research & Action Conference to Empower People with Disabilities. Older Adults and Caregivers. Proceedings, September 17-18, 2015; Washington, DC (www.icdr.acl.gov)

5. Source: Adapted from Administration for Community Living (http://www.acl.gov/NewsRoom/blog/2014/2014_07_09.aspx)