Advisory Council on Aging and Disability Services

Advocating for local, state, and national programs that promote quality of life for older adults and people with disabilities in partnership with Seattle Human Services and King County.

Advisory Council Meeting Minutes
January 12, 2024

Present: Patricia Schnephf; Marli Larimer; Joe Hailey; Clara Berridge; Irene Stewart; Joel Domingo; Maria Langlais; Michael Adusah; Hannah Kimball; JJ Wong; Vedrana Durakovic; Mary Mitchell; Waing Waing; Traci Adair; Mariel Torres Mehdipour; Tanya Kim; Kim-Khánh Văn; Eldad Mekuria; Karen Winston; Lorna Stone; Zelda Foxall; Cindy Snyder

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WELCOME
The Chair confirms that there is a quorum of voting members present at the start of this meeting.

Presentation: On Artificial Intelligence (Dr. Clara Berridge)
- Dr. Berridge is an Assistant Professor in the School of Social Work at the University of Washington. https://socialwork.uw.edu/faculty/professors/clara-berridge

The presentation focused on technology (AI specifically) and its impact and benefit to us with main takeaways being:
- Older adults want more control over digital technologies used in their care and decision about use.
- Caregivers require education about AI tools, including knowledge about ethical issues and how to navigate them.
- Data privacy (data mining) is unprotected at the Federal level, and AI is underregulated. We need privacy legislation as well as strong AI legislation.
- AI hype and the "innovation in aging" discourse should not drown out critical questioning.
- Questions for agencies to ask to help guide discussions and ethical issues.

A discussion was held after the presentation with highlights including:
- There is a need to incorporate the requirement for public participation into law and there needs to be an incentive for that and privacy data regulation at the federal level is overdue.
- Apprehensions about using AI are not about someone adverse to working with technology and concerns about AI use are valid regardless of a person's age. There are few studies which take older adults AI privacy concerns (privacy threats) into account. https://medium.com/datasociety-points/we-need-to-talk-about-digital-ageism-21e4c0c7dff3
- The term Ambient Criminalization refers to the surveillance of (low-wage workers) who are expected to be doing something wrong (such as cameras in nursing homes used to detect or

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prevent abuse leading workers to know there's an assumption that they don't respect the care relationship.) https://www.statnews.com/2024/01/11/health-records-ai-tools-social-determinants-health/ and https://datasociety.net/library/electronic-visit-verification-the-weight-of-surveillance-and-the-fracturing-of-care/

Please see the attached presentation for more details.

Race and Social Justice Moment: Using Your Voice is a Political Choice
A video https://www.ted.com/talks/amanda_gorman_using_your_voice_is_a_political_choice was sent out prior to the start of the meeting and a discussion was held during the meeting with major takeaways being:
- Voices can be a political force that can affect the current and new generations.
- We should not be fearful of having political conversations with each other. Shared value is important.
- Poetry (all art) is political. In countries where information is suppressed, they take away literature and poetry first.
- The poem given during the Biden Inauguration was inspirational.
- *I Too Sing America* by Langston Hugues is political, but it tells a lot of people's stories.

ADVISORY COUNCIL BUSINESS
I.   ACCEPTANCE OF PRIOR MEETING MINUTES (Joe Hailey)

MOTION: A vote was taken to approve minutes from the meeting held December 8, 2023. The minutes were accepted with added comment: The word "yes" under report by Michael Adusah (page 4) needs to be corrected.
Move to Accept: Barb Williams
Seconded: Lorna Stone
Outcome: The December 8, 2023, approved minutes will be corrected and posted after this meeting.

II.   REPORTS FROM COMMITTEES AND COUNCILS

Advocacy Committee (Barb Williams)
- The WA State Legislative Session began January 8, 2024. Michael Adusah created a spreadsheet for tracking the bills the Council need to put efforts into. This document will be kept updated through the course of the 60-day Legislative Session.
- A webinar on two W4A Supplemental Budget Items (Senior Nutrition and Case Management) takes place next week.

See attached 2024 Bills list for information on bills and initiations we're tracking. This list is currently in draft form, with content subject to change.

See attached Advisory Committee Meeting Minutes for more information.

Planning and Allocations Committee (Lorna Stone)

- Planning and Allocation meetings are scheduled to begin in February.

VSHSL Board Seniors Committee (Cindy Snyder)
- The December meeting did not occur, meeting next week.

NW Universal Design Council (Tom Minty)
- Planning for 2024 and are working on updating our website.
- Hope to have a Happy Hour next month and will post details once available.
- Giving Universal Design Presentation to the Executive Council for South King Housing and Homeless Partners and will post details once available.

Mayor's Council on African American Elders (Karen Winston)
- Presentation given on 2024 Advocacy Items during the December Meeting and discussion on how MCAAE and the Advisory Council can combine advocacy efforts in the future.
- The Annual Retreat takes place this month where new officers will be chosen, and the structure of the commission and 2024 monthly meeting dates will be discussed.

Age-Friendly Seattle (Eldad Mekuria)
- Reaching out to multiple commissions with a plan to start discussions in February. If AC members would like to volunteer as a Board-Peer Ambassador, email Michael Adusah and we'll make sure members have what you need to co-host the discussions.
- Civic Coffee: https://www.agingkingcounty.org/calendar/?ill_calendar_event_id=17948

III. **REPORTS FROM AAA PARTNERS**

King County Department of Community and Human Services (Traci Adair)
- The VSHSL was adopted by the council in mid-December.
- Contracts are continuing and are working on obtaining strategies for senior centers.
- Partnering with the City of Seattle to create King County Senior Centers Network.
- Moving towards helping community-based organizations having shared data opportunities for senior enters with different contracts.
- The SharePoint site is being updated and the Implementation Plan will be shared soon.

Public Health Seattle-King County (Michael Adusah)
- COVID In-home Vaccinations available if eligible. Flyers are available in 22 languages.
- WA Department of Health is offering free Telehealth Appointment for COVID-19 treatments.
- Free At-Home COVID-19 Test Kits available to order via COVID.gov.

Sound Cities Association (Andie Parnell)
- No updates provided this month.

IV.   APPROVAL OF NEW 2024 OFFICERS (Michael Adusah)
MOTION: A vote was taken to approve slate of officers for 2024 Advocacy Committee as follows:

- **Chair:** Alex O'Reilly;
- **Vice-Chair:** Lorna Stone (will continue);
- **Advocacy Committee:** Diana Thompson (on temporary basis);
- **Secretary:** Barb Williams; **At-Large:** Zelda Foxall.
- **Move to Accept:** Barb Williams
- **Seconded:** Marli Larimer
- **Outcome:** The slate of 2024 Officers as presented above, is approved. Information on newly elected officers will be updated where applicable by Michael Adusah after this meeting.

V.   ADS DIRECTOR'S REPORT (Mary Mitchell)

- Two Legislative Requests (Senior Nutrition and Case Management) will be presented at the W4A Advocacy Webinar with Kate White Tudor on January 16, 2024. *See attached Advisory Committee Meeting Minutes for more information.*
- February 22, 2024, W4A is hosting Advocacy Week. Email Michael Adusah for information.
- Washington is looking at becoming an Age Friendly state. We have an amazing program in ADS and are excited to see how we're going to be able to partner and provide the workplan we've laid out to help support expanding Age Friendly across the state.
- Presentation on Human Center Assisted Technology is being brought to W4A to see how we can support having more protections around AI.
- The ADS Leadership Team has filled all our vacant positions. We're moving forward on our Strategic Plan and how to support the community more as we look at our internal processes.
- We have 2-3 Case Management vacancies (down from 18).
- The state is researching having a statewide system to increase access to home-care agencies. ADS is developing a system (built on SharePoint) which will help streamline the process.

HSD DIRECTOR'S REPORT (Tanya Kim)

- The new Chair for the Housing and Human Services Committee is CM Cathy Moore who will represent the Advisory Council moving forward: https://www.seattle.gov/council/meet-the-council#moore
- Tanya and Kathy will meet to discuss the work we're doing and to clarify the alignment of that work as it pertains to CM Moore's priorities.
- HSD has an open position for Deputy Director in the Human Services Department: https://www.governmentjobs.com/careers/seattle/jobs/4340734/deputy-director

Meeting Adjourned

Advisory Council on Aging and Disability Services

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Advocacy Committee Meeting Minutes
January 12, 2024

Present: Barb Williams; Zelda Foxall; Maria Langlais; Alex O'Reilly; Diana Thompson; Joe Hailey; Vedrana Durakovic, JJ Wong, Deborah Hughes; Hannah Kimball; Michael Adusah

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The Chair confirms that there is a quorum of voting members present at the start of this meeting.

1. **ACCEPTANCE OF PRIOR MEETING MINUTES** (Joe Hailey)

   MOTION: A vote was taken to approve minutes from the meeting held December 8, 2023. The minutes were accepted without added comment.
   Outcome: The December 8, 2023, approved minutes will be posted after this meeting.

2. **ADVISORY COUNCIL CHCECK-IN**

   Zelda Foxall
   - Article in Seattle Times: https://www.seattletimes.com/seattle-news/homeless/homeless-people-are-getting-older-but-age-appropriate-help-is-limited/
   - Top Priorities for AARP are Access to Technology (to ensure people have access and know how to use it), the Ground Ambulance Bill and the Hospital at Home Program.

   Alex O'Reilly
   - Signed in as pro on the Rent Stabilization Bill and the Federal W4A OOA MILOE.
   - Involved in the Retired Public Employees Council of Washington and attending the state Virtual Lobby Day January 22, 2024.
   - Signed in as pro on Federal Bill (HR 5378) for improving transparency for hospital cost of care.
   - Working with ADS Staff and King County Assessor's Office on having presentations at senior centers to talk about Property Tax Relief Program changes.

   Diana Thompson
   - Leading the Advocacy Committee at Bellevue Network on Aging for many years, and finally has someone who agreed to take on this work.

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Joe Hailey

- Volunteering with the Center for Ethical Leadership: https://www.ethicalleadership.org/

Barb Williams

- Attended the Senior Lobby which included a presentation with W4A Food Lifeline ask.
- Signed in on several bills, with focus on issues that overlap ADS priorities and climate issues.
- Attending a DEI workshop next week at Town Hall.
- Asking the group to discuss the Right of Residence Long-Term Facilities Bill (HB 1859) and bring it to the full body to send support of this bill.

JJ Wong

- Following up with the new City Council Member and how they are coming into their positions.

Deborah Hughes

- Works for the Urban League of Metropolitan Seattle (seniors who are homeowners) to help prevent homelessness issues.

Hannah Kimball

- Completed 16th year working on BNOA . Volunteers at North Bellevue Community Center and is a food-bank farmer who works in a volunteer operation that supplies the Redmond Hopelink Foodbank with organic produce.

Vedrana Durakovic Sound Generations

- Has been doing advocacy work with Seattle Human Services Coalition for the last few years and is organizing a group to go to Olympia to attend the Legislative Session.

ADVOCACY ISSUES

State

- The W4A is going to Olympia the week of February 22, 2024, and there is interest in attending. Hunger Advocacy Day is February 2, 2024, and it could be an opportunity to go to Olympia.

Local
Council Membership:

- Over seventy applications were received for membership. We have six new Council Members. Cathy Moore was confirmed as Advisory Council Representative. Cathy is from District 5 which has one of the highest populations of low-income seniors in the city.

Funding Priorities:

- **Senior Nutrition:** https://www.agingwashington.org/media/dynamic/files/483-2024-senior-nutrition-final-for-coalition-1.7.24.pdf
  - Would like to see data added to the Senior Nutrition handout (above) showing how many people benefit. What is the baseline, how much of a loss does it represent to the agency (percentages/real numbers), how many people serving today, how many will you serve in the future? What is the current scenario and impact if we don't get this money?
  - Waitlists for people who have need for Meals on Wheels discussed at the Senior Lobby Conference in October. Sound Generations says there are more than eight-hundred people on the MOW waitlist as of a few months ago (it's estimated 3-years to clear the waitlist).
- **Case Management:** https://www.agingwashington.org/media/dynamic/files/482-2024-w4a-case-management-askclients-without-caregivers-12.19.23.pdf

Legislative Bills:

- Sign up to receive notifications on upcoming hearings and bills: https://leg.wa.gov/
- Six initiatives are on the ballot this fall that may change or undo legislation from the past few years. One is the WA Cares Fund (optional program versus required payroll deduction). We believe this will be put forward to allow the public to weigh in on portability.
- Capital Gains will have a massive impact on the state budget if it's overturned.

See attached 2024 Bills list for information on bills and initiations we're tracking. This list is currently in draft form, with content subject to change.

3. **CLOSING**

   Review of Action Items:
   - No updates were provided.

   Meeting Adjourned

Appropriations

Bill	Subject	Sponsor	Status	Notes
Budget Proviso	AAA Senior Nutrition	Van De Wege + Rep. Chapman	$7 million of the $15.2 million was in governors budget	Waiting to see if this will be a bill or a budget line item
Budget Proviso	AAA Case Management	Tharinger + Muzzall		Waiting to see if this will be a bill or a budget line item

Long Term Care/Healthcare

Bill	Subject	Sponsor	Status	Notes
HB 2272	Implementing LTC trust commission recommendations: boost benefit access, introduce voluntary private market LTC insurance, pilot program for trust assessment, streamline admin for fairness.	Macri	Jan 10 First reading, referred to Health Care & Wellness.	
SB 6075	Concerning sanctions of health care providers for violations of chapter 9.02 RCW.	Padden, Fortunato	Jan 9 First reading, referred to Law & Justice.	
HB 1859				

Digital Equity

Bill	Subject	Sponsor	Status	Notes
SB 5943	Developing a resource data tool to connect Washington residents to services and resources.	Hasegawa	Jan 18 Scheduled for public hearing in the Senate Committee on Human Services at 8:00 AM	

Consumer Protections

Bill	Subject	Sponsor	Status	Notes
HB 1933	Supporting the servicing and right to repair of certain products with	Gregerson,Kretz, Fitzgibbon,	Jan 12 Scheduled for public hearing in the House Committee on Consumer Protection &	W4A/ADS support

HB	digital electronics in a secure and reliable manner		Business at 8:00 AM (Subject to change). (Committee Materials) Jan 17 Scheduled for executive session in the House Committee on Consumer Protection & Business at 1:30 PM (Subject to change). (Committee Materials)	

Elections & Democracy

Bill	Subject	Sponsor	Status	Notes

Progressive Revenue

Bill	Subject	Sponsor	Status	Notes
HB 1075	Expanding eligibility for the working families' tax credit to everyone age 18 and older.	Macri, Gregerson Bergquist,	Jan 8 By resolution, reintroduced and retained in present status.	Will have major impact on seniors
HB 1702	Imposing a local sales tax wholly credited against the state sales tax to support programs for senior citizens.	Orcutt, Abbarno, Volz, Jacobsen	Jan 8 By resolution, reintroduced and retained in present status.	Companion Bill: SB 5686

Affordable Housing and Homelessness

Bill	Subject	Sponsor	Status	Notes
HB 1998	Concerning co-living housing	Gregerson	Jan 11 Executive action taken in the House Committee on Housing at 8:00 AM	Companion Bill: SB 5901
SB 5961	Improving housing stability for tenants subject to the residential	Hasegawa	Jan 12 Scheduled for public hearing in the Senate Committee on Housing at 10:30 AM	Companion Bill: HB 2114

	landlord-tenant act and the manufactured/mobile home landlord-tenant act by limiting rent and fee increases, requiring notice of rent and fee increases, limiting fees and deposits, establishing a landlord resource center and associated services, authorizing tenant lease termination, creating parity between lease types, and providing for attorney general enforcement.		

Initiatives

The takeaways

- Older adults, including people living with dementia, want more control over digital technologies used in their care and decisions about use

- Frontline staff require education about AI tools, including knowledge about the ethical issues and how to navigate them

- Data privacy is unprotected at the federal level and AI is underregulated

- <u>We need privacy legislation as well as strong AI legislation</u>

- AI hype and the "aging-and-innovation" discourse should not drown out critical questioning

- There are several questions all organizations/agencies should be asking now…

Concerns at CMS about passive monitoring (2014)

Medicaid HCBS Waivers

- How do we know what is being used with beneficiaries?
- Does it produce or intensify isolation?
- What are the ethical implications?
- Privacy?

Key Findings: State Medicaid HCBS analysis (2016)

—2/3rds of the 15 states covered location tracking and activity-monitoring sensors; 1/3rd covered cameras

—Only 3 states had service categories to track when they are paying for any of these

—**Consideration of ethical issues was limited**

—**States struggled to understand which circumstances warrant use and to train staff about tech**
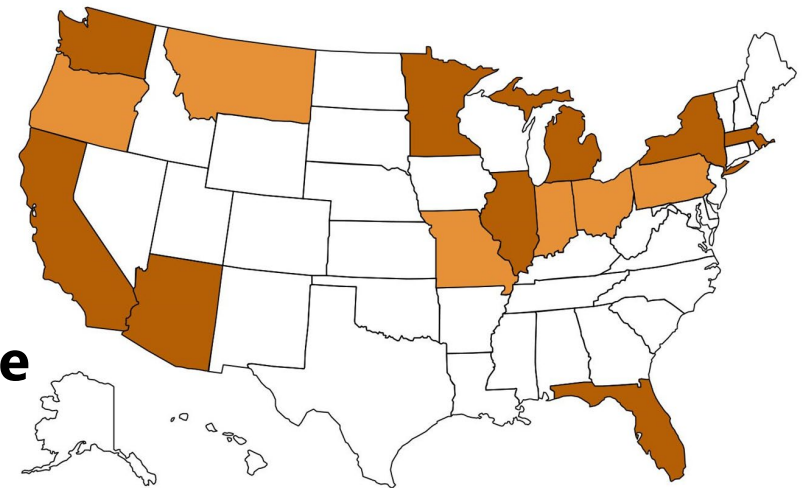
Berridge, C. (2018). Medicaid becomes the first third-party payer to cover passive remote monitoring for home care: Policy analysis. *Journal of Medical Informatics Research* (JMIR)

State Medicaid analysis of home and community-based services waivers

"There's a consent factor there, and understanding if the person knows they're being monitored, and if their representative is solely safety-driven and doesn't include evaluation of dignity at risk. So there are a lot of factors. How informed is the person?"

-state Medicaid waiver manager

Berridge, C. (2018). Medicaid becomes the first third-party payer to cover passive remote monitoring for home care: Policy analysis. *Journal of Medical Informatics Research* (JMIR)

Clara Berridge | University of Washington School of Social Work

a 2023 National Association of Social Workers webinar on AI

72% rated their knowledge of AI as "low"

1% rated it "high"

-automation:

    often, the use of algorithms to classify (e.g., for targeted advertising), suggest (e.g., Netflix), or make consequential decisions (e.g., screening, allocating benefits)

-facial recognition

-generating synthetic media (text or images) using large language models (i.e., ChatGPT, Bard)

UnitedHealth pushed employees to follow an algorithm to cut off Medicare patients' rehab care

By Casey Ross ✔ and Bob Herman ✔ Nov. 14, 2023

ars TECHNICA

BIZ & IT   TECH   SCIENCE   POLICY   CARS   GAMING & CULTURE

DESPICABLE —

UnitedHealth uses AI model with 90% error rate to deny care, lawsuit alleges

For the largest health insurer in the US, AI's error rate is like a feature, not a bug.

BETH MOLE - 11/16/2023, 3:37 PM

UnitedHealthcare

With Labor Department Focus on Tech, Unemployed New Yorkers Can't Reach Human Agents

A Rochester man lost his job while his daughter went through cancer treatment. He's struggled to communicate with the DOL for months.

MAXWELL PARROTT · DECEMBER 5, 2023
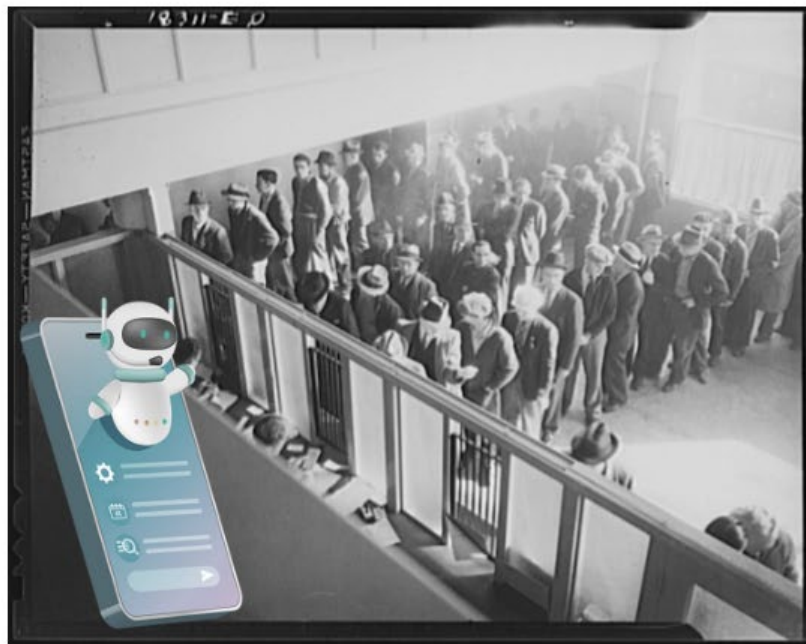
The Department of Labor encourages claimants to use an AI chatbot rather than calling. | Photo: Dorothea Lange / Library of Congress | Illustration: Maia

TECHNOLOGY

Eating disorder helpline takes down chatbot after it gave weight loss advice

JUNE 8, 2023 · 4:21 PM ET

HEARD ON ALL THINGS CONSIDERED

"Algorithmic decision-making is predisposed to inflict harm if it is introduced to triage support in a benefits system that is chronically underfunded and set up to treat beneficiaries as suspects rather than rights-holders.

By contrast, benefits automation is more likely to promote transparency, due process, and "equitable outcomes" if it is rooted in long-term investments to increase benefit levels, simplify enrollment, and improve working conditions for caregivers and caseworkers" (Toh, 2024).

Toh, A. (January 4, 2024). The Algorithms Too Few People Are Talking About LAWFARE. The Lawfare Institute and Brookings: https://www.lawfaremedia.org/article/the-algorithms-too-few-people-are-talking-about

Study: Some AI chatbots provide racist health info

Maya Goldman, author of Axios Vitals

Illustration: Maura Losch/Axios

ACLU

About

NEWS & COMMENTARY

Algorithms Are Making Decisions About Health Care, Which May Only Worsen Medical Racism

Unclear regulation and a lack of transparency increase the risk that AI and algorithmic tools that exacerbate racial biases will be used in medical settings.

Some of the most high-profile artificial intelligence chatbots churned out responses that perpetuated false or debunked medical information about Black people, a new study found.

11

Inaccurate and misleading anthropomorphizing descriptions:

ascribing empathy

understanding

thinking

"brain power"

...sentience

Automation bias is the tendency of people to assume that computers are objective, authoritative, and fair, even when there is evidence to the contrary.

It causes someone to go along with a machine's output even if it doesn't sit right with them.

Automation bias is the tendency of people to assume that computers are objective, authoritative, and fair, even when there is evidence to the contrary.

It causes someone to go along with a machine's output even if it doesn't sit right with them.

People are still driving into lakes because their GPS tells them to

Yoni Heisler
May 17, 2016

GPS Directs Two Drivers Into Hawaii Harbor

In the span of one month, two vehicles have ended up in Kailua-Kona's Honokohau Small Boat Harbor—and allegedly it's all thanks to GPS.

By Adrianna Nine May 31, 2023

Democratizing AI requires public participation

- "Access to government services and benefits

- Gathering and retention of biometric, health, or other sensitive personal information

- Surveillance of vulnerable populations

- Policing functions of the state, such as law enforcement and child welfare

- Gatekeeping access to life necessities such as housing, credit, education, employment, and health care"

Copied from Michelle Gilman, Sept 27, 2023, Democratizing AI: Principles for Meaningful Public Participation. Policy brief. Data & Society

Large language models

- ChatGPT and other tools use code to read and generate plausible text (it's a machine learning model)

- This is a "system for manipulating text" built to "provide a plausible continuation of some input prompt (*what's the likely next word, what's the likely next word*...). The problem is it is so plausible that we interpret it as if it's language, and we do that by imagining there's a mind behind it" (Emily Bender, 2023).

- They are <u>optimized for plausibility – not for accuracy</u>.

Large language models

- Open AI and other companies refuses to release details about their training data.

  - Because different patterns will emerge from different data sets, it matters what the source data are.

- Harms can't be mitigated when you don't know what the training data is.

- Dominant LLMs are likely trained on words written by majority white, majority male, with resources (e.g., Reddit, Wikipedia, public social media accounts).

Examples of unresolved problems & ethical concerns with LLM uses

Treatment recommendations w/out proper validation/oversight leads to harms

Hallucinations, fake "information"

Accountability is not properly assigned. Unregulated – no recourse for harm

Copyright violation and plagiarism

Harmful content (violent, offensive)

Bias (design, training data)

Labor exploitation (outsourced human work to identify toxic/illegal material)

Over-reliance (lack of verification)

Privacy problems

Explanatory understanding is lacking

Inaccurate AI-generated text/images pollute information ecosystem – deteriorating public trust in information/media

Environmental costs (i.e., water for cooling and other resources)

CrunchBase and Digital Health Report HealthXL & AARP: Enabling connected and independent living through new care models
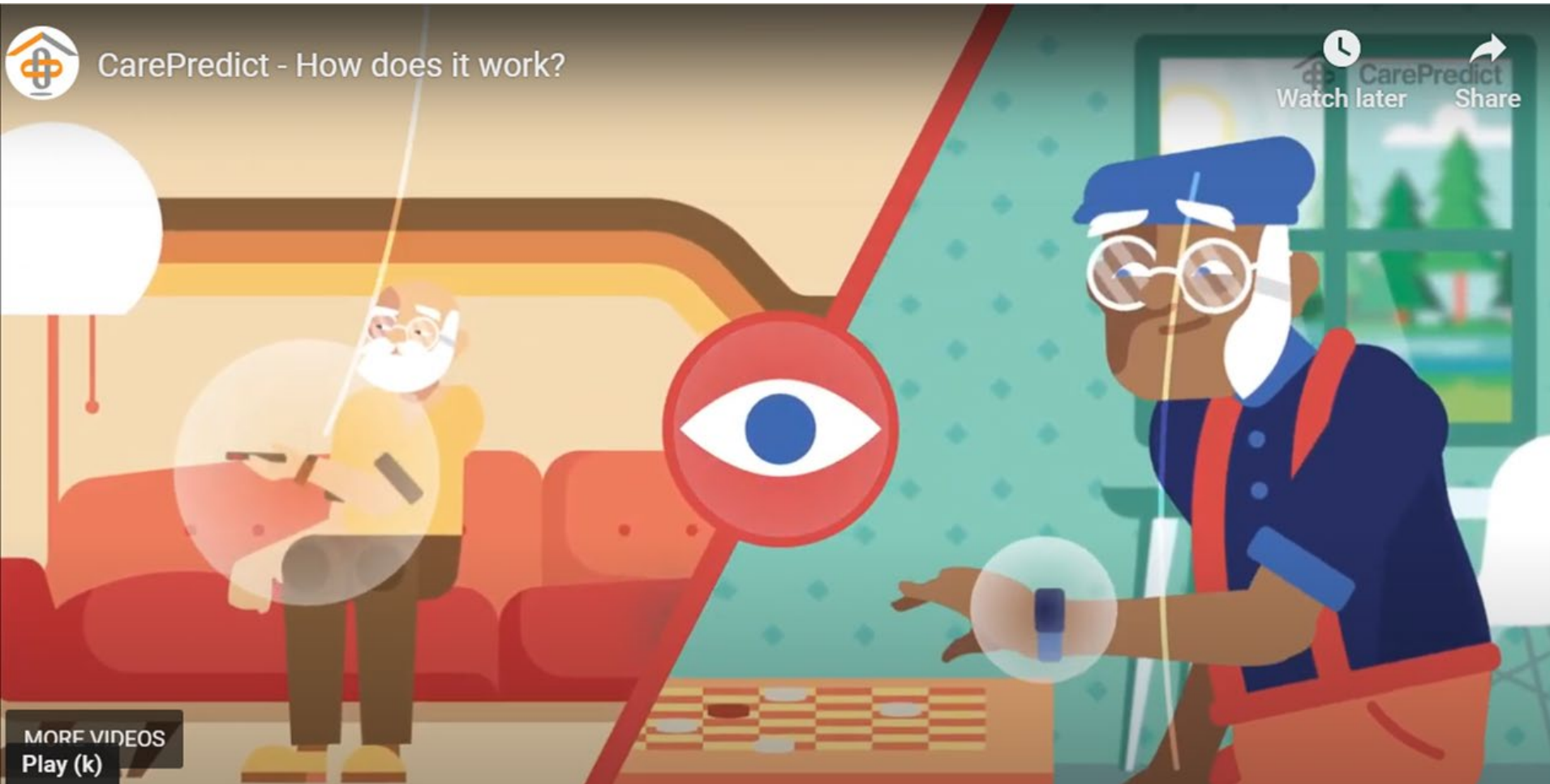
"...gathering data at every second to observe each elderly person through their daily activities. To identify and chart their individual behavior patterns to spot any significant deviation."

"Making the whole system as sharp and individually vigilant as no single caregiver–either family related or professional–could ever manage to be."

24/7 Notifications for Staff Efficiency

Caspar provides 24/7 notifications and automated check-ins. The real-time dashboard allows staff to provide care to residents more effectively.

Even with 1 less FTE, staff provides better care to residents.

The Triple Win
of the aging-and-innovation discourse

Neven, L., Peine, A. (2017). From triple win to triple sin: How a problematic future discourse is shaping the way people age with technology. *Societies*

Clara Berridge | University of Washington School of Social Work

The problem

- Ethics conversation on gerontechnology was slow to get started

- We are now aware of numerous risks and value tensions (Mortenson, Sixsmith, Woolrych 2015; Novitsky et al., 2015, Ienca et al., 2019; Ho, 2020; Lariviere et al., 2021; Higgs 2022)

- But there is a significant gap between the research on ethical issues and design, real-world implementation, policy, and practice

What's at stake for older adults in decisions about how technologies are used in their care?

Lariviere, M. et al. (2021). Placing assistive technology and telecare in everyday practices of people with dementia and their caregivers: findings from an embedded ethnography of a national dementia trial. *BMC Geriatrics*

Those most likely to cause value tensions

- Recording audio in a person's home to respond to emergencies, monitor socialization, detect cognitive change

- Video conferencing allowing a caregiver to turn the webcam on and "enter" the room visually for social connection and visual assessment

- Location tracking outside the home

- Location tracking inside the home to monitor safety and social activity, variation in activity

- Using an AI virtual agent or socially assistive robot for non-human companionship to ease loneliness or prompt engagement

- Remotely monitoring physiological variables for frequent assessment to predict and manage health risks

Berridge, C., Demiris, G. & Kaye, J. (2021). Domain Experts on Dementia-Care Technologies: Mitigating Risk in Design and Implementation. *Science & Engineering Ethics*

Common risks of dementia care technologies (1/4)

—privacy invasion for individual and visitors

—feeling uncomfortable/bugged/no place to hide

—infantilize or lead to feeling "baby sat"

—compromise one's dignity

Berridge, C., Demiris, G. & Kaye, J. (2021). Domain Experts on Dementia-Care Technologies: Mitigating Risk in Design and Implementation. *Science & Engineering Ethics*

Common risks (2/4)

—caregiver stress from ambiguous data/alert overload

—false sense of security, reducing proactive help

—reduction of visits or calls, leading to loneliness

Berridge, C., Demiris, G. & Kaye, J. (2021). Domain Experts on Dementia-Care Technologies: Mitigating Risk in Design and Implementation. *Science & Engineering Ethics*

Survey comments on importance of human connection

"All of these artificial companions provide the illusion of intimacy without actual intimacy. That's dishonest - and creepy."

"The answers to the problems implicit in these prompts cannot be found on robots - they can only be found in the difficult, and necessary, work of restructuring our society so that people who need it always have in-person support."

"We need to temper AI with HI-Human Intelligence systems that are financially supported and that provide healthy human interactions rather than pretending that Alexa is your 'friend.' That is AI jail keeping, not community building."

Berridge, C., Zhou, Y., Robillard, J., Kaye, J. (2023). Companion robots to mitigate loneliness among older adults: perceptions of benefit and possible deception. *Frontiers in Psychology*

Common risks (3/4)

—tension caused by caregiver paternalism in form of intrusive or harassing questioning

—caregiver limits freedom, using data to rebuke, restrict, or micromanage

—behavior change to conform w/ expectations

Berridge, C., Demiris, G. & Kaye, J. (2021). Domain Experts on Dementia-Care Technologies: Mitigating Risk in Design and Implementation. *Science & Engineering Ethics*

Common risks (4/4)

– data lead to knowledge of non-adherence or high risk activities that lead to increased premiums or denial of coverage

– data security risk & nefarious use

– unknown or unsanctioned third party use (companies monetizing data)

Berridge, C., Demiris, G. & Kaye, J. (2021). Domain Experts on Dementia-Care Technologies: Mitigating Risk in Design and Implementation. *Science & Engineering Ethics*

Example of data privacy and use concerns

"Overall I like the idea of an AI companion or device to check-in on a family member. Particularly to alert medical services and family if an emergency arises. However, I have concerns about how that data is being stored and used by third party companies. Far too often that data is not being stored securely and being sold to third party companies for data aggregation."

-survey participant

Berridge, C., Zhou, Y., Robillard, J., Kaye, J. (2023) AI companion robot data sharing: comfort and preferences of an online cohort with policy implications. *Journal of Elder Policy*

Limited protections against harm and privacy violation (U.S.)

- "Notice and consent" leaves burden on the user/consumer

- Under HIPAA regulations, companies making direct-to-consumer devices are not covered entities, despite the use of health information (Ho, 2023) (Berridge, 2023, p38).

- There is no requirement that developers provide privacy policy statements in the U.S., or make them widely comprehendible (Ho, 2023; Lupton & Jutel, 2015).

Ho, Anita (2023). Live Like Nobody is Watching: Relational Autonomy in the Age of Artificial Intelligence Health Monitoring. Oxford University Press

Berridge, C., Zhou, Y., Robillard, J., Kaye, J. (2023) AI companion robot data sharing: comfort and preferences of an online cohort with policy implications. *Journal of Elder Policy*

Limited protections against harm and privacy violation (U.S.) cont'd

- Data sharing practices matter to people but are inadequately communicated to them (Berridge, 2023, p38).

- Ex: most health apps focused on dementia require explicit entry of personal information (Ye et al., 2023)–and most lack a privacy policy and admit to possible data sharing with outside parties (Rosenfeld et al., 2017).

- Companies under no obligation to do bias assessments (of their algorithm) or otherwise assess social impact

U.S. Federal AI Guidance

Blueprint for an AI Bill of Rights (2022)
White House Office of Science and Technology Policy

- Automated systems and technology-based efficiencies *tempered by civil rights and democratic value concerns*

- *Safe & Effective Systems* (proactive protections, independent evalu.)

- *Algorithmic Discrimination Protections* (unjustified impacts/ treatment based on classifications protected by law (i.e., race, color, ethnicity, sex, religion, age, disability, etc.) equity assessments, algorithmic impact assessment & mitigation info

- *Data Privacy* (ethical review, use prohibitions, civil rights/liberties)

- *Notice & Explanation* (automated system, how and why impacts you)

White House Executive Order on AI

October 30, 2023

-charges federal agencies with drafting guidelines for responsible AI and taking steps to regulate and review its applications

-requires an immediate "talent surge" at these agencies

-implementing the directives?

Resources: Organizations, media, and advocacy groups

- Center for Democracy and Technology (CDT)
- Tech Policy Press
- Center for Critical Race & Digital Studies (*People's Guide to Finding Algorithmic Bias*)
- Our Data Bodies
- AI Now
- Berkman Klein Center for Internet & Society
- The DAIR Institute
- All Tech is Human
- Data & Society
- Allied Media Projects/Detroit Digital Justice Coalition
- Design Justice Network

Specific suggested resources

→ **Examples of how AI touches marginalized communities:**
Poverty Lawgorithms by Michelle Gilman. Data & Society report.
https://datasociety.net/library/poverty-lawgorithms/

→ **To better understand large language models:**
Watch*: "ChatGP-Why"* presentation by Drs. Emily Bender and Alex Hanna
https://www.youtube.com/watch?v=qpE40jwMilU

Their podcast: *Mystery AI Hype Theater 3000:*
https://www.buzzsprout.com/2126417

→ **Advice for intentional language use about AI:**
Artifice and Intelligence by Emily Tucker. Tech Policy Press:
https://www.techpolicy.press/artifice-and-intelligence/
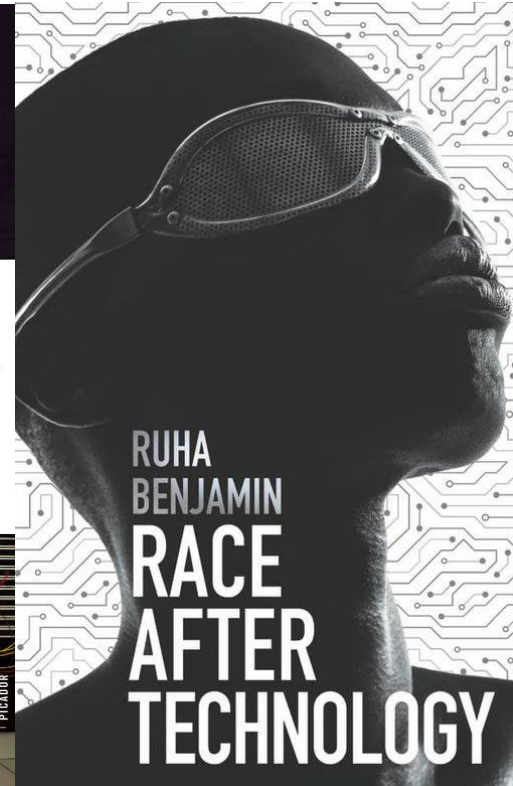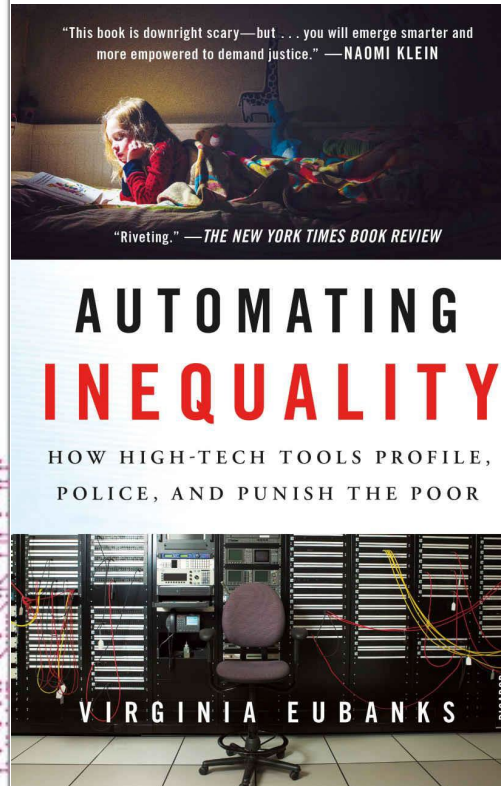
→ **Up-to-date discussion of new devices on the market:**
Aging & Health Technology Watch: https://www.ageinplacetech.com/

- How were end users and impacted people involved in design and development?
- <u>What's being automated, why, and who benefits from this automation?</u>
- Is this the way we want to achieve this goal?
- How is success and accuracy measured exactly? <u>What are the evaluation metrics?</u>
- <u>How well does it work in the specific case we're using it for?</u>
- Where does accountability lie when something goes wrong?
- <u>How does a person with few financial resources report harm or error?</u> What is the recourse?
- Are the people using and impacted by a given AI tool informed about its use and implications?
- <u>What data was the AI tool trained on?</u> What or who is excluded?
- How much money is invested in this?
- What are the potential opportunity costs?
- Does this address the underlying problem? Does this enable the underlying problem to persist?
- Does this allow us to address structural problems? Does it obscure underlying structural problems?

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Thank you

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Articles cited here that I've co-authored can be found, open access, on my faculty page:
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