



ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES
THE LEADERSHIP, EDUCATION, ADVOCACY & RESEARCH NETWORK

Aging SIG 2019 Notes

Participants: Tamar Heller, Beth Marks, Matt Janicki, Bill Gaventa, Kelli Barton, Kelly Hsieh, Elaine Brown, Lieke Van Heumen, Ryan Rausch, Michelle Rubenstein, Donna Bainbridge, Yumi Shirai, Flip Grey, Sharon Milberger, Jasmina Sisirak, Sue Fox, Lynne Tomasa, Tiffanie Katsuva, Jennifer Rabalais, Michelle Aguigui, Meg Traci, Dawn Rudolph

Discussion:

Lieke Van Heumen: Health & Aging Policy Fellow, a non-residential (part time) fellowship. All Fellows went to DC for orientation, spent time in DC last year, lots of briefings from Congressional Research Service, attended House hearing and Senate trials for impeachment. Fellows can be placed in legislative or executive branch, or with non-profits or elsewhere. Exciting to be part of this program and bring disability perspective; intersection of aging & disability. Lieke started with Senator Casey's office in January 2020; fully remote since mid-March. Last day in his office will be 11/13. Work has focused on aging services, esp. Area Agency on Aging in PA, focused mostly on nutrition, incontinence and social isolation. Coordinated roundtable of most AAA agencies in PA for stakeholder feedback. Focus on how to serve individuals long term. Also spoke with Council on Aging in PA. Senator Casey led efforts to have findings inform Families First and CARES Act appropriations. Held hearing on social isolation in seniors; Lieke did background research on social isolation to prep him for hearing including questions for witnesses, briefing on background, etc. Also been working on issue of incontinence as half of aging community experience incontinence. Supplies are not covered by Medicare and are expensive. Stigmatized issue. Senate appropriations committee briefings; requested CDC update report from 2014 on incontinence; it made it in! Looked to see which populations are at higher risk for incontinence and how to support them. Giving a plug for the Fellowship program – great exposure to policy, changed how I see the work and engage on these important issues. Applications for 2021-2022 program due in April; Lieke is happy to talk with anyone interested.

Beth Marks & Jasmina Sisirak: Health Matters Program including Healthy Brain Initiative and Virtual Coach. Healthy Brain Initiative is CDC-funded 5-year project. See attached ppt titled *AUCD Aging SIG HBI and Virtual Coach HealthMatters FINAL (11-12-20)* for details.

Matt Janicki – CDC is looking at how to make this project work for people not traditionally engaged including historically underserved communities.

Meg Traci: NYT article (11/11/20), "Developmental Disabilities Heighten Risk of Covid Death. People with intellectual disabilities and developmental disorders are three times more likely to die of Covid-19, compared with patients without the conditions, a new analysis found..." "There

is no question,” said Arthur Caplan, director of medical ethics at the New York University Grossman School of Medicine. “These people are high risk and must be given priority for vaccination.” <https://www.nytimes.com/2020/11/10/health/covid-developmental-disabilities.html>. Hearing concerns about people with DD who have DNR orders in place are having DNR invoked unnecessarily during pandemic.

Tamar Heller: Bridging Aging & Disability International – international interest group has been going on for a while, Tamar co-chairing along with Michelle Putnam at Simmons College in Boston. Previously was funded by Canada March of Dimes. Will set up new website, will be resource for finding out what’s going on internationally

Phil McCallion received the Lifetime Achievement award from Disability Section of APHA

Meta-analysis of family caregiving in older adults in Annual Review of Psychology
<https://www.annualreviews.org/doi/abs/10.1146/annurev-psych-010419-050754>

Minnesota doing survey on aging & retirement – coming soon to listserv

Bill Gaventa: working as consultant with Nancy Lurie Marks Family Foundation in conjunction with Hospice Foundation of America on resource for grief and loss for people with disabilities. Website will have 4 people and their friends and caregivers of different faiths, looking for stories that might serve as vignettes addressing people with autism dealing with grief and loss. Also looking for autistic artist to create logo for site. See attachment titled *Autism Bereavement Project Logo Design Call for Submissions* for more info and dissemination.

Lynne Tomasa: research project on sexual violence. Interviews, forums, trainings. Would love to talk with anyone who has done work in this area, contact ltomasa@arizona.edu

Bibliography of articles on COVID & IDD online at <https://www.the-ntg.org/> – helpful for citations for articles and other work. Direct link = https://2e626e23-9885-43be-a9e4-d60d120ed14f.filesusr.com/ugd/8c1d0a_c9adae07b0904928909f7b93ac375f3f.pdf

Donna Bainbridge: aging population of Special Olympics athletes, looking at proposal addressing aging athletes such as fitness for sport and open to hearing thoughts and ideas to dbridge@blackfoot.net

December 10, 4-4.45 ET, the AAIDD Health and Gerontology Divisions are hosting a webinar by Dr. Phil McCallion on COVID-19, dementia and people with IDD. Here is the link to register: https://us02web.zoom.us/webinar/register/WN_0_0Ro0uZSliLFHIS27zA8g

Lieke on Year 2 of funding from Special Olympics re: health related topics for athletes, overwhelming response that topic of aging is important, need more information on how to stay active while aging