

Aging SIG notes
11/7/17

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What's happening in the network bridging aging & disability?

- Nat'l Alzheimer's Program Act (NAPA) – 4 states included people with DD in their state plans, using materials from National Task Group for aging & disability
- Fall prevention efforts funded by ACL – now focusing on disability and aging (formerly just aging)
- Aging & Disability Resource Centers (ADRC) bridges, though D is small
- Aging community trying to learn from disability community re: person-centered planning
- Grief, loss, and end of life issues
- Aging parents with ataxia
- Public health, education, nutrition – addressing how older people process information differently
- Transition to work efforts starting to see folks 50+ wanting to enter the workforce, worried about social security benefits not sustaining them, not eligible for Medicaid/Medicare if haven't invested enough in them over years
- Got a goal for aging into UCEDD 5-year plan:
 - o When do people with IDD retire? Some folks don't want to retire, as work is their social life
 - o End of life and grieving process
- Kelly Nye-Lengerman (MN) had poster on retirement of people with IDD. Seeing move to day programs starting retirement programs.
- Curriculum: person centered planning for end of life
- Roger Stancliffe has curriculum in Australia: transition to retirement: see Tamar Heller's testimony document
- CA – how to get adult day health care centers (ADHC)? Often not prepared to take people with disabilities. Any successes anywhere?
 - o Tamar: peer mentors help support integration of people with disabilities one at a time, rather than a busload of folks showing up.
 - o Some Arc programs are setting up retirement day programs, but these are segregated
 - o Reminiscence therapy, other approaches learned from nursing homes

- Look at assets and resources in community, look up community approaches
- futures planning (Tomas) being updated with ABLE Act, sexuality, overall a broader view
- Dementia capable care – NTG training in Tucson and Phoenix – very high demand, hardly have to advertise. Very good program!
- Arizona has had one institution open for years, as promised to family. Folks living there have very high support needs. Population diminishing as folks age & pass away, no one new moving in. Contract with DD Agency to develop person centered plans to move folks out into community settings
- WI: NIH Institutional K award - training in geriatrics, using Medicaid data, using national Medicare data set, and health system in northern Wisconsin to see service needs of people with autism. Early stages of intervention development with aging people with autism, as well as health disparities. Breaking new ground with this research
- Many folks aging with autism were diagnosed with schizophrenia when younger, 1940s or so
- Able to identify people with autism through review of Electronic Health Records (EHR)
- Doc student interested in doing systematic review of end of life service needs of people with ID. Teresa Savage has done some of this (@ UIC nursing), also Moro @ Rush University, also check with Phil Davidson (Rochester NY) and Bill Gaventa. Leigh Ann Kingsbury's work in end of life, published by AAIDD. Also look at work by Sandy Friedman's (CO) work
- CA: work on aging caregivers – working with minority parent groups very concerned by being in 80's or 90's with 60 year old kids with disabilities at home, worried about what to do when they die. CA now requires that data be published on services provided by race, ethnicity, age. Doing workshop for Vietnamese aging families with disabilities; may be able to be tweaked for other Asian groups.
- Futures Now train-the-trainer model being rolled out as part of Family Support RTC in IL
- Center for Future Planning with the Arc – could be geared to a particular racial/ethnic group
- FL: Interest in health equity/disparities for people with ID, worked in Special Olympics, hard to find healthcare providers able to serve adults with disabilities – too many pediatricians still providing care to adults. Working on training medical students to treat adults with disabilities. Toolkit out of Vanderbilt available to provide free CMEs to train current physicians on treating adults with disabilities.
- Teach classes on aging & disability at UT Austin

Survey of healthcare decisionmaking and end-of-life care for people with disabilities

- See survey results provided by Georgetown University's Marisa Brown
- **Email End of Life resources to bishopfitzpa@wisc.edu**

Matt Janicki pulled together workgroup for Tamar Heller at Alzheimer's Assn, at same time on American Society on Aging. First time anything about ID was presented at Research Summit on Dementia Care: Building Evidence for Supports – gave 5-minute talk. Purpose was to develop RFPs for NIH, funders looking for recommendations on what to fund. Got ID into recommendations from workgroup. Many approaches from working with people with ID over the years also getting into recommendations such as translational research, communicating with pictures and other modes, etc. See report, including names of contributors. Report and ppts online at NIH

See Tamar Heller's Senate testimony on aging caregivers, health promotion, and retirement. Developed report, gave 5 minute talk. Senator Collins (ME) very interested in family caregiving. Also Senator Fisher (NE). Recommendations include inclusive design, transportation, respite act.

CA has caregiver resource centers (similar to family resource centers). If build support for aging caregivers, where does that support lie? Family resource centers often only do youth and transition age, not aging. What does National Family Caregiver Support Act do? Can fund programs, funds go to states. Funding from Dept of Mental Health, only for grandparents taking care of grandchildren. Think Family Resource Centers should do this.