# Health and Wellness – Strategic Brainstorm

1. Disability and Public Health
   1. Develop and public health & disability surveillance system for people with disabilities.
   2. Develop capacity at the state level with state agencies responsible for achieving health equity for individuals with disabilities.
   3. Examine morbidity and mortality differences between different groups (income, ethnicity) in people with and without disabilities.
   4. Infuse disability populations into federal initiatives on health and public health consistently and meaningfully. For example, the Surgeon General’s Call to Action on Walking and Walkable Communities does not include the population of people with disabilities in the goals and recommended action steps, but does refer to disability as a negative health outcome to avoid.
   5. Many researchers have noted the “aging tsunami,” but aging with a (congenital or acquired) disability is an overlooked issue.
   6. Delaying medical care because of cost is a problem for people with disabilities- what are the policy/program interventions that could address this problem?
2. Wellness
   1. We have very little preventive provider services directed for persons with disabilities. If we are to promote maximal quality of life, health care services need to focus on prevention of worsening of sequelae for persons with disability, both for children and adults.
   2. How to make sure that services needed to create a healthy life are studied. For example, gyms that support disability exercise do not exist. Especially in rural areas, people with disabilities have difficulty getting places.
      1. Presentation from the RERC on disability and exercise: <http://www.rectech.org/>.
   3. Wellness/Disabilities Centers:
      1. Not only disability centers for health care, but disability centers that allow for promotion of life quality and good coping strategies.
      2. Disability focused centers could serve as model to provide input. There are disability centers within Association of University Centers on Disabilities working on various issues.
   4. Smoking, obesity, diabetes, and people with disabilities -- research on prevalence and effective interventions
   5. Mental health: we have huge issues with mental health conditions that eventuate in permanent functional disabilities. We should not leave out a focus on mental health.
   6. Research on health disparities and health interventions needs to focus on subpopulation differences.
   7. Research is needed to identify and/or develop evidenced-based health transition programs for youth with disabilities.
   8. More sophisticated research is needed to determine the impact of disparities on negative health outcomes. For example, do lower rates of cancer preventive screening among persons with disabilities result in greater rates of morbidity and mortality?
3. Family and Community Issues
   1. In looking at the model, it is imperative that not only the patient is the focus of our consideration, but also the family.
      1. Most people with disabilities affect family life as families are heavily involved in management and impact of disabilities.
      2. There is opportunity to utilize community outreach workers.
      3. Consider not only the caregiver, but also how disability changes family life. For example, I have a family that when child’s equipment is in the car the whole family cannot fit, so someone must stay home.
   2. Support qualitative research that reflects stories of issues that people with disabilities and their families face. Really, a support of mixed methods.
      1. Translation research can look at best practices into community.
4. Health Care Provider Practices
   1. Cultural competency of disability among health care providers needs to be addressed.
      1. Dentists and oral health professionals are not trained appropriately to work with vulnerable populations, including those with disabilities.
      2. Workforce development might correct some of the disparity-inducing behaviors of providers and public health professionals.
      3. Women’s health and reproductive health can be a problem for women with disabilities. OB/GYN and FP clinics aren’t always equipped for physical disabilities, and aren't always prepared to discuss contraception/sexual health with adults with mental disabilities.
   2. Might be useful to augment secondary data analysis with primary data collection including impacts on sub-populations.
      1. There has been research on health provider practices, but is usually limited to MEPS and other secondary data rather than directly with providers.
   3. Focus on oral health, promoting action-focused research rather than documenting disparities.
5. Access to Health Care
   1. Not having access to adaptive equipment (wheelchair, accessible technology devices) is a barrier. Where does that barrier come from?
   2. Barriers to health care access often manifest as a local problem (inaccessible clinics, health care provider attitudes, transportation, etc.) but there is little research on local approaches to resolving access problems.
   3. How do we measure the cost as a nation not to successfully care for people with disabilities?
6. Research and Funding
   1. American Community Survey (ACS) disability identifiers in health surveys and surveillance is helpful, but disability is a complex construct. Eliminating additional identifiers/questions is premature and scientifically unsound.
   2. Research needs to untangle congenital, acquired, and disability derived from chronic conditions. Determining age of onset may help clarify this problem.
   3. Current postdoctoral training programs supported by NIDILRR are severely under-funded.
7. Emerging Issues
   1. Include multiple chronic conditions, as with many persons with disabilities, as the slide show indicated, a large impact is on MCCs.
   2. Environmental Sensitivity – both electrical sensitivity and chemical sensitivity.
      1. Consider developing an ICDR-inspired interagency committee to address this issue.
      2. Overlaps with issue raised in brainstorming of ICDR technology committee.