

To:

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We, the undersigned self-advocacy and disability advocacy groups write to you to support the HIT Policy Committee's Measure Concepts with some modifications to insure the quality of care of people with disabilities. We refer the Committee to Section 4302(a) of the Affordable Care Act, which states:

Understanding Health Disparities: Data Collection and Analysis  
Title IV, Subtitle D, Section 4302(a)

**Data collection and reporting on health care access and quality by race, ethnicity, and language and other factors such as health status or disability**

Collection Standards: In collecting data, the Secretary or designee also shall:

- 1) survey providers to assess access to care and treatment for individuals with disabilities and to identify
  - (a) locations where individuals with disabilities access primary, acute (including intensive), and long-term care,
  - (b) number of providers with accessible facilities and equipment to meet the needs of the individuals with disabilities, and
  - (c) number of employees of providers trained in disability awareness and patient care; and
- (2) require that reporting requirement imposed for purposes of measuring quality under any ongoing or federally conducted or supported health care or public health program includes requirements to collect data on individuals receiving health care items or services under such programs activities by race, ethnicity, sex, primary language, and disability status.

We believe that HIT and EHR have the power to collect aggregate data on people with disabilities to provide information to improve the quality of care of people with disabilities as ACA outlines. Further, Healthy People 2020 lists elimination of health disparities for people with disabilities and others and improving the health of all people among its four foundation health measures. We applaud the Committee's emphasis on patient empowerment and self-management. We appreciate the Committee's health equity measure. However, we believe

additional measures must be included to meet both ACA's and Healthy People 2020's goals of quality care and decreased disparities for people with disabilities.

According to the National Council on Disability (NCD), 2009 report, *The Current State of Health Care for People with Disabilities*, “[p]eople with disabilities experience significant health disparities and barriers to health care, as compared with people who do not have disabilities.” Basic primary care is not a guarantee for anyone in the disability community. (Drainoni M, Lee-Hood E, Tobias C, et al., 2006) Three out of five people with serious mental illness die 25 years earlier than other individuals, from preventable, co-occurring chronic diseases, such as asthma, diabetes, cancer, heart disease and cardiopulmonary conditions. (Colton & Manderscheid, 2006; Manderscheid, Druss, & Freeman, 2007) Inaccessible medical equipment and lack of trained physicians, dentists, and other health professionals prevent individuals with disabilities from receiving the basic primary and preventive care others take for granted, such as getting weighed, preventative dental care, pelvic exams, x-rays, physical examinations, colonoscopies, and vision screenings. (Kirschner, Breslin, & Iezzoni, 2007; Chan, Doctor, MacLehose, et al. (1999); Manderscheid R., Druss B., & Freeman E. 2007).

To address these concerns, quality measures need to address eliminating the barriers to quality care that people with disabilities now face. IT must collect basic data regarding this functional limitation of people with disabilities to enable quality measures to address efforts to improve the quality of health care provided.

The measure concepts should include measures of the social determinants of health as outlined in Healthy People 2020, since these determinants significantly affect access to and the quality of health care provided to people with disabilities. The measures concepts should also include measures of access to home and community based services for improved/sustainable community participation.

Since lack of access to basic primary care is a significant issue that often causes preventable secondary conditions, measure concepts should also include measures of equal access to primary care and related services (ie. Mammogram, colonoscopy) for people with disabilities. (See section 4302 of ACA). Further, while some may feel that the prevention of secondary conditions may fall under co-morbidities measure, we believe this must be a separate quality measure for people with disabilities so we can work in a meaningful way to prevent them.

Thank you for the opportunity to have input into this project. We appreciate your efforts and any of the undersigned organizations are happy to lend their expertise on health and disabilities to your efforts.

Sincerely,

ADAPT Montana  
Alliance for Disability in Health Care Education  
All About You Home Care  
American Association of People With Disabilities  
American Association on Health and Disability

American Medical Rehabilitation Providers Association  
American Network of Community Options and Resources  
The Arc of the United States  
Association of University Centers on Disabilities  
ATAP - The Association of Assistive Technology Act Programs  
Autistic Self-Advocacy Network  
Bazelon Center for Mental Health Law  
Brain Injury Association of America  
Bronx Independent Living Services  
California institute for Mental Health  
Center for Disability Rights (Rochester)  
The Center for Health Care Services  
Center for Independence of the Disabled, NY.  
CHADD – Children and Adults with Attention-Deficit/Hyperactivity Disorder  
Disability Policy Consortium  
Disability Rights Education and Defense Fund  
Disability Rights Wisconsin  
Easter Seals  
Harris Family Center for Disability and Health Policy at Western University of Health Sciences  
Institute for Human Centered Design  
Mental Health America  
National Alliance on Mental Illness (NAMI)  
National Association of Councils on Developmental Disabilities  
National Association of County Behavioral Health and Developmental Disability Directors  
National Association of Head Injury Administrators  
National Association of the Deaf  
National Organization of Nurses with Disabilities (NOND)  
National Spinal Cord Injury Association  
New Yorkers for Accessible Health Coverage  
Not Dead Yet Montana  
Regional Center for Independent Living (Rochester, NY)  
Salt Lake County, Division of Behavioral Health Services  
Silicon Valley Independent Living Center  
Spina Bifida Association  
Statewide Independent Living Council of GA, Inc.  
United Cerebral Palsy  
United Spinal Association  
Women with Disabilities Health Equity Coalition (WowDHEC)

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US. Department of Health and Human Services. Health People 2020. Improving the Health of Americans. <http://www.healthypeople.gov/2020/topicsobjectives2020/default.aspx>