

Comment on Notice of Availability of Proposed Data Collection Standards for Race, Ethnicity, Primary Language, Sex, and Disability Status Required by Section 4302 of the Affordable Care Act (Document ID HHS-OMH-2011-0013-0001).

According to the Report of the Surgeon General's Conference on Health Disparities and Mental Retardation (2002), health care costs for the 4.9% of the Medicaid population with intellectual disabilities account for 15.7% of total Medicaid expenditures. Individuals with intellectual and developmental disabilities are among the most challenging served and the most costly. Given the challenges facing this population and their caregivers, and the challenges faced by states and the federal government in funding both acute and life-long supports to this population under the Medicaid program, it is essential that valid and reliable data be gathered and utilized to shape effective public policy and manage service delivery. Current national data on the health needs and disparities for this population are inadequate, incomplete and of no value for policy planning or program management.

DHHS' proposed set of questions for persons with disabilities yield no information on the health status and needs of persons with intellectual and developmental disabilities, no data on characteristics, health access, needs or disparities and no information that can be operationally applied by states and the federal government to assess the achievement of health outcomes, costs or cost-drivers related to the provision of services to the 15.7% of the Medicaid population with the most intensive needs. In an effort to "promote a consistency in measurement and continuity in the dialogue" DHHS and OMB appears to have lost sight of the need for valid and useful information – information that can actually be applied by state and federal agencies to make a difference in the lives of the individuals being served and the ability of systems to deliver appropriate, effective and cost efficient services.

NASDDDS strongly recommends that the six question set be expanded to gather additional information on the presence of persons in the household with intellectual and developmental disabilities and related conditions such as cerebral palsy, epilepsy, autism, and others.

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