People with intellectual disabilities must be designated a medically underserved population

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It has been estimated that there are 6 million people in the United States with intellectual disabilities (ID). Access to care for individuals with ID falls far short of their medical and dental needs in primary, secondary, tertiary, and rehabilitative care. Although these individuals may face many of the same challenges in navigating the health care system as the general population, they are also dealing with health issues exacerbated by their specific pathophysiology and cognitive deficits. These factors often increase their risk and burden of disease, their likelihood of not seeking preventive or early treatment, and the inevitability of their experiencing far greater adverse effects such as recurrent infections and social isolation to name just a few. So with a tremendous national emphasis on health care reform and the goal of universally enhancing an individual's quality of life, what is the probability that people with ID will gain better access to care in the immediate future? Slim to none.

The four principal and interrelated factors that obstruct access to care for people with ID are professional attitudes, clinical competency, financial barriers, and public perception. Most health care providers receive little or no education in caring for people with ID during their formal training. The lack of adequately trained and willing providers is the single greatest barrier to care for people with ID. From a provider's financial standpoint, there is a complete lack of incentives to treat this patient population and the existing public programs are poorly funded with below average reimbursements. On the patient side of the balance sheet, having a child with ID is costly and can directly impact a family's stability and decline toward poverty. The general public's impression is that people with ID have greater access to care, which is based largely on the national prominence of health screening programs like Special Olympics Healthy Athletes. However, the public's view is overly optimistic and not in line with reality. So how, at an institutional level, can the government remove many of these barriers to care for people with ID?

People with ID must be formally designated by the U.S. Government as a medically underserved population (MUP). Population groups seeking MUP designation must have economic barriers (low-income or Medicaid-eligible populations), or cultural and/or linguistic barriers to primary medical care services. The U.S. Department of Health and Human Services established criteria for designation of MUPs based on the Index of Medical Underservice (IMU). The IMU is calculated via a four-step process. The first calculation is the weighted value for poverty and is based on the percent of the population with incomes at or below 100% of the poverty level in the area of residence for the population group. The second calculation is the weighted values for percent of population age 65 and over. The third calculation is the infant mortality rate. The fourth and final calculation is the ratio of the full-time equivalent (FTE) primary care physicians serving the population group per 1000 persons in the group. If the total weighted values V1–V4 is 62 or less, the population group qualifies for designation as an IMU-based MUP. However, under the provisions of Public law 99-280, enacted in 1986, a population group which does not meet the established criteria of an IMU less than 62 can nevertheless be considered for designation if “unusual local conditions which are a barrier to access to or the availability of personal health services” exist and are documented.

When the IMU is computed for people with ID, it is 54.2, yet despite the recommendations from HRSAs own Advisory Committee on Training in Primary Care Medicine and Dentistry, the federal government has yet to designate this population as a MUP. The MUP designation can benefit practitioners who care for an underserved population in many ways. Often, student loan repayment programs are available to practitioners who focus on serving an MUP. Special research grants are directed toward researchers who study MUPs. Even Medicaid reimbursements can be enhanced under specific programs focused on serving MUPs. These benefits ultimately translate into greater access and better quality care for the patient population in question.

In 2010 the Secretary of Health and Human Services appointed a Negotiated Rulemaking Committee on the Designation of Medically Underserved Populations “to consider and develop new methodologies for designating medically underserved communities and populations.” The process has reached an impasse. Regardless of the "new math" that will probably evolve from this reconsideration one thing remains consistent, people who are medically underserved are people who do not receive ongoing, competent, collaborative and comprehensive healthcare oversight and intervention, and that defines, describes and demarcates individuals with ID. No formulas, equations, coefficients, or footnotes will change that reality. It’s time to put the pens down and address the stark reality that as a nation we are not supporting, honoring and caring for our most vulnerable population.
The American Medical Association with guidance from the American Academy of Developmental Medicine and Dentistry and Special Olympics passed resolution 805-I-10 through the AMA House of Delegates stating that people with ID should be viewed as an MUP. It is now organized dentistry’s turn to step up to the plate and swing for the fences. It is a win–win proposition for both dentists and people with ID.

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References