REPORT OF THE COUNCIL ON MEDICAL SERVICE

CMS Report 3-I-11

Subject: Designation of the Intellectually Disabled as a Medically Underserved Population (Resolution 805-I-10)

Presented by: Thomas E. Sullivan, MD, Chair

Referred to: Reference Committee J (Barbara J. Arnold, MD, Chair)

At the American Medical Association’s (AMA) 2010 Interim Meeting, the House of Delegates referred Resolution 805-I-10, which was introduced by the International Medical Graduates Section and calls for the AMA to “lobby Congress to work with the appropriate federal agencies, such as the Department of Health and Human Services, to classify intellectually disabled persons as a medically underserved population.” The Board of Trustees referred Resolution 805-I-10 to the Council on Medical Service for study.

This report provides background on intellectual disabilities, discusses how the federal government currently designates a group as a medically underserved population, highlights Patient Protection and Affordable Care Act (ACA, PL 111-148) provisions that are likely to impact individuals with intellectual disabilities, reviews relevant AMA policy, and presents policy recommendations.

BACKGROUND

Approximately seven to eight million Americans of all ages experience some level of intellectual disability (American Association on Intellectual and Developmental Disabilities, 2009). An intellectual disability – sometimes referred to as a cognitive disability or “mental retardation” – is an impairment that manifests before adulthood and limits mental functioning indefinitely. The degree of disability can vary greatly and be categorized as mild, moderate, severe, or profound based on the ability to communicate, socialize and perform activities of daily living. Some of the most commonly known causes of intellectual disability may be attributed to genetics, infections during pregnancy and problems at birth or factors during childhood.

Over the past 50 years, care for those with intellectual disabilities has shifted from institutions to the mainstream community. Individuals with intellectual disabilities are more likely to receive fewer routine health examinations, fewer immunizations and less prophylactic oral health care than do other Americans. As noted in Resolution 805-I-10, employment and low-income status are key barriers to health care access for individuals with intellectual disabilities. Lower socioeconomic standing, related to poor employment prospects, results in a greater reliance on government-funded programs (e.g., Medicare, Medicaid, the Children’s Health Insurance Program, local community clinics, county medical centers, federally qualified health centers and safety net clinics).

HEALTH RESOURCES AND SERVICES ADMINISTRATION

The Department of Health and Human Services (HHS) oversees the Health Resources and Services Administration (HRSA), which is the primary federal agency designed to administer the primary
care Health Professional Shortage Area (HPSA) designation system. Since the 1970s, the HPSA designation system has expanded to nearly 30 programs that can be divided into four broad categories: 1) primary care service grants; 2) health professionals training and recruitment support; 3) Medicare and Medicaid payment enhancements; and 4) support for international health professional graduates. HPSA designations are specifically used by programs such as the J-1 Visa waiver program and the Federally Qualified Health Care (FQHC) program to address health care access and physician payment barriers. The J-1 Visa program allows international medical graduates to qualify for a waiver of the two-year foreign residency requirement if they commit to serve in a medically underserved area or population or in a HPSA facility for at least three years. The primary care FQHC program directs primary care physicians to medically underserved areas, populations and facilities.

There are three types of HPSA used to prioritize the distribution of federal and state funds based on medical need: geographic, population-group, and facility. Geographic HPSAs, designated as medically underserved areas (MUAs), include entire counties, a portion of a county, or a group of contiguous counties. Population-group HPSAs, designated as medically underserved populations (MUPs), include groups, such as migrant farm workers, low-income urban populations, or federally recognized Native American Tribes or Alaska Natives, within particular geographic areas. Facility HPSAs include federal or state correctional institutions, health centers, and certain rural health clinics.

To receive HPSA designation, the requesting agency or individual must provide HRSA with information demonstrating that the area, population group, or facility meets applicable criteria (General Accounting Office, “Health Professional Shortage Areas,” 2006). Developed over 30 years ago, policymakers and patient advocates have periodically questioned the designation methodology. Congress has been hesitant to initiate changes that may be technically and politically complex and would affect the financing of more than 30 federal programs.

THE MEDICALLY UNDERSERVED POPULATION (MUP) DESIGNATION

To designate individuals with intellectual disabilities as a “medically underserved population,” HRSA would need to specifically identify the group in its definition. The formula for MUP designation is comprised of four variables, that when added together, represent the extent to which a population is underserved. These four variables are: (1) the ratio of primary care physicians to 1,000 individuals in the population with incomes at or below 100 percent of the federal poverty level in a specific area, (2) the percentage below the federal poverty level, (3) the percentage aged 65 and older, and (4) the infant mortality rate. In 2004, the American Academy of Developmental Medicine and Dentistry (AADMD) used these four variables to determine that the intellectually disabled population should be designated a medically underserved population. Although the request was submitted to HRSA, the AADMD reports no formal response to the request.

The ACA requires HRSA to replace the medically underserved designation methodology through the negotiated rulemaking process. Accordingly, in 2010, HRSA convened the Negotiated Rulemaking Committee on Designation of Medically Underserved Populations and Health Professional Shortage Areas to initiate a review of MUP designation criteria. As part of its review, a subcommittee was established to focus on the health care access issues of populations with special needs. The subcommittee has considered changing the designation process by separating the criteria into three groups: regular, simplified and streamlined. Individuals with intellectual disabilities would potentially meet the simplified criteria designation process based on existing federal legislation (i.e., the Americans with Disabilities Act of 1990 amended by the American with Disabilities Act of 2008, PL 110-325, the Combating Autism Act of 2006, PL 106-426, the
Developmental Disabilities Act of 2000, PL 106-402, and the Traumatic Brain Injury Act of 2008, (PL 110-206). Individuals with intellectual disabilities are already assumed to meet the criteria related to health status, access to care and poverty, and would only need to demonstrate low provider availability at local levels. The HRSA Negotiated Rulemaking Committee’s final report is expected in the fall of 2011, and HHS is projected to publish an interim-final regulation during the spring of 2012.

THE IMPACT OF ACA

Several key provisions of the ACA address coverage, access, underlying population health and investments in workforce, all of which are likely to benefit individuals with intellectual disabilities. These provisions include:

- Preventing health plans from limiting or denying enrollment of children under the age of 19 due to a pre-existing condition;
- Preventing health plans from setting lifetime dollar limits;
- Requiring health plans to cover wellness and preventive services;
- Requiring health plans to make coverage available to children up to age 26;
- Expanding health insurance coverage to 32 million Americans;
- Investing in innovations such as medical homes and care coordination demonstrations in Medicare and Medicaid with the goal of preventing disabilities from occurring and progressing;
- Creating temporary high-risk pools and health insurance exchanges; and
- Authorizing $50 million to integrate primary and specialty care services in community-based mental and behavioral health settings.

The Council is hopeful that these provisions, taken together, will improve the health care of those with intellectual disabilities.

RESOLUTION 805-I-10

During testimony on Resolution 805-I-10, speakers expressed concerns about how “intellectually disabled” would be defined for the purposes of identifying a new MUP. As noted, several laws have attempted to address access to care for individuals with intellectual disabilities and a HRSA Negotiated Rulemaking Committee is reviewing its designation process.

The resolution also highlights several socioeconomic barriers that can prevent individuals with intellectual disabilities from obtaining appropriate access to care. During testimony, questions were raised about whether a MUP designation would actually improve access. The Council believes that while a MUP designation could focus resources on individuals with intellectual disabilities, it is unlikely that a new designation alone would foster optimal health care access.

An equally salient concern is whether there are adequate educational opportunities for those who care for the intellectually disabled. A 2005 survey conducted jointly by the American Academy of Developmental Medicine and Dentistry and the Special Olympics found that 52 percent of medical school deans, 56 percent of students, and 32 percent of medical residency program directors responded that graduates were “not competent to treat people with neurodevelopmental disorders or intellectual disabilities.” In addition, 81 percent of medical students surveyed reported receiving no clinical instruction in treating individuals with neurodevelopmental disorders and intellectual disabilities, and 66 percent reported that they were not receiving adequate classroom instruction.
The study also indicated that the lack of training is not linked to discrimination or unwillingness to treat individuals with intellectual disabilities; most medical students are interested in providing care as part of their career (Special Olympics, 2005; Wolff, Waldman, et al., 2004).

AMA POLICY

Several key AMA policies promote the goals of Resolution 805-I-10. For example, the AMA supports health system reform alternatives that are consistent with AMA policies concerning universal access for patients, insurance market reforms that expand choice of affordable coverage and eliminate denials for pre-existing conditions or due to arbitrary caps, and investments and incentives for quality improvement and prevention and wellness initiatives (Policy H-165.838, AMA Policy Database).

The AMA also has several policies that specifically advocate for improving care to those with intellectual and developmental disabilities. The term “developmental disability” encompasses both intellectual and physical disabilities. Policy H-90.975 advocates for the highest quality medical care for persons with profound developmental disabilities; encourages support for health care facilities whose primary mission is to meet the health care needs of persons with profound developmental disabilities; encourages medical school faculty and trainees to deliver care to persons with profound developmental disabilities and multiple co-morbid medical conditions; encourages medical schools and graduate medical education programs to train medical students and residents in caring for the developmentally disabled; and encourages the use of available resources related to profound developmental disabilities.

Policy D-270.997 advocates for funding for training physicians in the care of “mentally retarded”/developmentally disabled individuals, increasing the reimbursement for the health care of these individuals; and advocates that insurance industry and government reimbursement reflect the true cost of health care of “mentally retarded”/developmentally disabled individuals. In addition, Policies D-90.996 and H-290.982 similarly refer to “mentally retarded” individuals.

Policy H-200.992 urges the federal government to consolidate the federal designation process for identifying areas of medical need; coordinate the federal designation process with state agencies to obviate duplicative activities; and ask for state and local medical society approval of said designated underserved areas.

DISCUSSION

Resolution 805-I-10 highlights the need for a robust effort to increase the number of physicians and other health care professionals able to provide care to individuals with intellectual disabilities. Using the HRSA designation criteria to designate individuals with intellectual disabilities as an MUP is a potential avenue to increase the supply of physicians providing care among those individuals who are uninsured. Previous attempts to revise the designation process to recognize individuals with intellectual disabilities as medically underserved have been slow, and the success of current efforts to modify the designation methodology had not been finalized at the time that this report was written.

The Council is aware that special populations including individuals with intellectual disabilities are being considered by the HRSA Negotiated Rulemaking Committee for designation as a “medically underserved population.” Extending the designation of MUPs may provide incentives to physicians who care for individuals with intellectual disabilities. Given that the Committee’s formal proposal will not be available until the fall of 2011, the Council recommends that the AMA
support a simplified process across appropriate federal agencies to designate individuals with intellectual disabilities as a medically underserved population.

In the broader context of improving access to care for individuals with intellectual disabilities it is unlikely that a population-based designation alone would significantly increase access to needed health care. Consistent with Policy H-165.838, the AMA advocates health system reform principles that support providing health insurance coverage for all Americans, enacting insurance market reforms that expand choice of affordable coverage, eliminate denials for pre-existing conditions or due to arbitrary caps, provide investments in incentives for initiatives that improve quality and enhance prevention and wellness – all of which are principles included in the Affordable Care Act. The Council is hopeful that such a comprehensive approach will improve health care for the sickest and poorest Americans.

The absence of professional training on disability competency and poor provider payment are barriers that prevent individuals with intellectual disabilities from receiving appropriate medical care. Policy D-270.997 advocates for funding for training physicians in the care of “mentally retarded” individuals and also advocates for increase provider payments to reflect the true cost of providing health care. The Council believes that Policy D-270.997 addresses these barriers and recommends that it be editorially revised to use the term “individuals with intellectual disabilities,” instead of “mentally retarded.”

The Council notes that Policies H-290.982[16] and D-90.996 similarly identify individuals with intellectual disabilities as “mentally retarded,” and recommends that all policies be editorially revised to reflect the more culturally sensitive terminology of “individuals with an intellectual disability” or “intellectual disability.”

RECOMMENDATIONS

The Council on Medical Service recommends that the following be adopted in lieu of Resolution 805-I-10, and that the remainder of the report be filed:

1. That our American Medical Association support a simplified process across appropriate government agencies to designate individuals with intellectual disabilities as a medically underserved population. (New HOD Policy)


Fiscal Note: Staff cost estimated to be less than $500 to implement.

References are available for the AMA Division of Socioeconomic Policy Development.