

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)

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

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

12 BACKGROUND

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

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

32 HEALTH RESOURCES AND SERVICES ADMINISTRATION

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35 The Department of Health and Human Services (HHS) oversees the Health Resources and Services
36 Administration (HRSA), which is the primary federal agency designed to administer the primary

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

12
 13 There are three types of HPSA used to prioritize the distribution of federal and state funds based on
 14 medical need: geographic, population-group, and facility. Geographic HPSAs, designated as
 15 medically underserved areas (MUAs), include entire counties, a portion of a county, or a group of
 16 contiguous counties. Population-group HPSAs, designated as medically underserved populations
 17 (MUPs), include groups, such as migrant farm workers, low-income urban populations, or federally
 18 recognized Native American Tribes or Alaska Natives, within particular geographic areas. Facility
 19 HPSAs include federal or state correctional institutions, health centers, and certain rural health
 20 clinics.

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

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 29 **THE MEDICALLY UNDERSERVED POPULATION (MUP) DESIGNATION**

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 31 To designate individuals with intellectual disabilities as a "medically underserved population,"
 32 HRSA would need to specifically identify the group in its definition. The formula for MUP
 33 designation is comprised of four variables, that when added together, represent the extent to which
 34 a population is underserved. These four variables are: (1) the ratio of primary care physicians to
 35 1,000 individuals in the population with incomes at or below 100 percent of the federal poverty
 36 level in a specific area, (2) the percentage below the federal poverty level, (3) the percentage aged
 37 65 and older, and (4) the infant mortality rate. In 2004, the American Academy of Developmental
 38 Medicine and Dentistry (AADMD) used these four variables to determine that the intellectually
 39 disabled population should be designated a medically underserved population. Although the
 40 request was submitted to HRSA, the AADMD reports no formal response to the request.

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 42 The ACA requires HRSA to replace the medically underserved designation methodology through
 43 the negotiated rulemaking process. Accordingly, in 2010, HRSA convened the Negotiated
 44 Rulemaking Committee on Designation of Medically Underserved Populations and Health
 45 Professional Shortage Areas to initiate a review of MUP designation criteria. As part of its review,
 46 a subcommittee was established to focus on the health care access issues of populations with
 47 special needs. The subcommittee has considered changing the designation process by separating
 48 the criteria into three groups: regular, simplified and streamlined. Individuals with intellectual
 49 disabilities would potentially meet the simplified criteria designation process based on existing
 50 federal legislation (i.e., the Americans with Disabilities Act of 1990 amended by the American
 51 with Disabilities Act of 2008, PL 110-325, the Combating Autism Act of 2006, PL 106-426, the

1 Developmental Disabilities Act of 2000, PL 106-402, and the Traumatic Brain Injury Act of 2008,
2 PL 110-206). Individuals with intellectual disabilities are already assumed to meet the criteria
3 related to health status, access to care and poverty, and would only need to demonstrate low
4 provider availability at local levels. The HRSA Negotiated Rulemaking Committee's final report
5 is expected in the fall of 2011, and HHS is projected to publish an interim-final regulation during
6 the spring of 2012.

7 8 THE IMPACT OF ACA

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

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

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

29 30 RESOLUTION 805-I-10

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

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

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43 An equally salient concern is whether there are adequate educational opportunities for those who
44 care for the intellectually disabled. A 2005 survey conducted jointly by the American Academy of
45 Developmental Medicine and Dentistry and the Special Olympics found that 52 percent of medical
46 school deans, 56 percent of students, and 32 percent of medical residency program directors
47 responded that graduates were "not competent to treat people with neurodevelopmental disorders
48 or intellectual disabilities." In addition, 81 percent of medical students surveyed reported receiving
49 no clinical instruction in treating individuals with neurodevelopmental disorders and intellectual
50 disabilities, and 66 percent reported that they were not receiving adequate classroom instruction.

1 The study also indicated that the lack of training is not linked to discrimination or unwillingness to
2 treat individuals with intellectual disabilities; most medical students are interested in providing care
3 as part of their career (Special Olympics, 2005; Wolff, Waldman, et al., 2004).

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5 **AMA POLICY**

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

13
14 The AMA also has several policies that specifically advocate for improving care to those with
15 intellectual and developmental disabilities. The term “developmental disability” encompasses both
16 intellectual and physical disabilities. Policy H-90.975 advocates for the highest quality medical
17 care for persons with profound developmental disabilities; encourages support for health care
18 facilities whose primary mission is to meet the health care needs of persons with profound
19 developmental disabilities; encourages medical school faculty and trainees to deliver care to
20 persons with profound developmental disabilities and multiple co-morbid medical conditions;
21 encourages medical schools and graduate medical education programs to train medical students and
22 residents in caring for the developmentally disabled; and encourages the use of available resources
23 related to profound developmental disabilities.

24
25 Policy D-270.997 advocates for funding for training physicians in the care of “mentally
26 retarded”/developmentally disabled individuals, increasing the reimbursement for the health care of
27 these individuals; and advocates that insurance industry and government reimbursement reflect the
28 true cost of health care of “mentally retarded”/developmentally disabled individuals. In addition,
29 Policies D-90.996 and H-290.982[16] similarly refer to “mentally retarded” individuals.

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

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36 **DISCUSSION**

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

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

1 support a simplified process across appropriate federal agencies to designate individuals with
2 intellectual disabilities as a medically underserved population.

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

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

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

26 RECOMMENDATIONS

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29 The Council on Medical Service recommends that the following be adopted in lieu of Resolution
30 805-I-10, and that the remainder of the report be filed:

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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)
 2. That our AMA editorially revise Policies D-90.996, D-270.997 and H-290.982[16] by insertion of the term “individuals with intellectual disabilities” and deletion of the term “mentally retarded.” (Modify Current 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.