

The Case for Designating People with Intellectual and Developmental Disabilities as a Medically Underserved Population

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Introduction

The federal government defines “medically underserved populations” (MUP) according to a formula that weighs a population’s lack of primary care providers, its experience with poverty and increased infant mortality, and its percentage of people age 65 and older.¹ As a population, people with intellectual and developmental disabilities (I/DD) meet most of these criteria. Two Surgeons General Reports and a report of the National Council on Disabilities document that people with intellectual and developmental disabilities (I/DD) experience significant health disparities, poorer health, and lack access to care.²⁻⁴ The published literature and public health survey data continue to support these findings of poorer health in general, including poorer health outcomes, higher prevalence of adverse, chronic, and/or secondary conditions, and increased mortality.⁵⁻⁷ Few primary care providers and few specialists are available, trained, or have time to treat, people within the I/DD population.⁸⁻¹¹ Many children and adults with I/DD live in poverty.^{12,13} There is a significantly high incidence of infant mortality in the I/DD population as a whole.¹⁴⁻¹⁶ People with I/DD are living longer and living into their 60s.¹⁷

However, the federal government ultimately defines “medically underserved population” (MUP) in terms of a group that occupies the same neighborhood, community, census tract or geographic area.^{18,19} This puts people with I/DD in a Catch-22. Though as a population, people with I/DD experience a lack of primary care providers, significant rates of poverty, increased infant mortality, and an aging population; the I/DD population can never meet the MUP designation standard because they do not live together in segregated communities. This means that as integrated members of society woven throughout the fabric of our country, people with I/DD cannot receive the many benefits other medically underserved populations receive to remedy their health disparities and lack of access to health care.

The United States Department of Health and Human Services’ Health Resources and Services Administration (HRSA) current MUP designation system ultimately is based on locale. The I/DD population used to be housed separately at one time. Forty years of civil rights advocacy proved segregated living discriminatory.

...people with intellectual and developmental disabilities ... experience significant health disparities, poorer health, and lack access to care.

The Autistic Self Advocacy Network (ASAN) is a non-profit organization run by and for autistic people. ASAN provides support and services to individuals on the autism spectrum while working to change public perception and combat misinformation. Our activities include public policy advocacy, community engagement to encourage inclusion and respect for neurodiversity, quality of life oriented research and the development of autistic cultural activities. www.autisticadvocacy.org

Anti-discrimination laws allowed people with I/DD to integrate into society. For HRSA to require people with I/DD to live together in order to achieve a MUP designation seems to violate federal law and international policy that promotes the integration of individuals with I/DD into society.²⁰ The designation of a MUP should be based on unmet needs—not where people live.

Two alternative routes to MUP designation exist for the I/DD population. Individual governors can request the Secretary of the United States Department of Health and Human Services (HHS) designate the I/DD population a MUP in their own state, based on the lack of available primary care providers trained to treat this population.²¹ Alternatively, Congress could legislatively designate the I/DD population as a “special medically underserved population,” a designation currently shared by populations comprised of “migratory and seasonal agricultural workers, the homeless, and residents of public housing.”²² The I/DD population’s needs closely resemble the needs of these other legislatively designated “special medically underserved populations” and as such, its needs also must be met within the bounds of a civilized society.

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Background

History of the MUP Designation

Congress began the health center programs in the 1960s to respond to the large number of people who lived in medically underserved areas, and the growing number of special populations that lacked access to preventive and primary health care services.²³ The programs sought “to empower communities to solve their own local access programs and to improve the health status of their underserved and vulnerable populations by building community-based primary care capacity and by offering case management, home visits, outreach, and other services.”²³

Between 1962 and 1990, four separate programs were developed under four different laws to serve the medically underserved: The Migrant Health Center program in 1962; Community Health Centers first funded in the mid-1960s as neighborhood health centers; Health Care for the Homeless funded in 1987; and Health Services for Residents of Public Housing, passed in 1990.²³ In 1996, Congress passed the Health Centers Consolidation Act (HCCA) to consolidate, streamline, and reauthorize the four Federal health center programs under one authority, Section 330 of the Public Health Service Act (PHSA). For the first time under HCCA, Section 330 put three programs together—“migratory and seasonal agricultural workers, the homeless, and residents of public housing” under the umbrella of “special medically underserved populations.”²³ Congress enacted and reauthorized the Native Hawaiian Health Care Improvement Act several times and through this and a Congressional special initiative, HRSA included Native Hawaiians under its special populations programs.²⁴⁻²⁶

Populations that do not fall under the umbrella of ‘special medically underserved population’ must meet the criteria for the “Medically Underserved Populations.” The current designation process for ‘Medically Underserved Populations’ dates back to 1975.¹ In 1973 and 1974, legislation was passed that established grants to support Health Maintenance Organizations and Community Health Centers (CHCs) (previously ‘neighbor-hood health centers’) to serve medically underserved populations.¹ The MUP criteria was issued to implement this legislation.¹

One additional route exists to achieve the MUP designation for populations not included in the ‘special medically underserved populations’ or those that do not meet the MUP designation criteria. In 1986, Congress added a permissible designation criteria, sometimes called the Governor’s Exceptional Medically Underserved Population (EMUP) that allows governors to request the designation from the Secretary of HHS under certain circumstances.^{21,27,28}

Guidelines for MUP Designation

“Medically underserved population” means the population of an urban or rural area designated by the Secretary of HHS as an area with a shortage of personal health services or a population group designated by the Secretary as having a shortage of such services.²⁹ The PHSA directed the Secretary of HHS to develop criteria to determine specific shortages of personal health services of an area or population group based on the four following criteria:

1. health status of a population group or residents of *an area*,
2. the ability of the residents of *an area* or of a population group to pay for health services and
3. their accessibility to them, and
4. the availability of health professionals to residents of *an area* or to a population group.³⁰

(numbers and emphasis added)

The Secretary of HHS developed the guidelines to establish the MUP designation incorporating the above criteria and based on the Index of Medical Underservice (IMU) first published in the Federal Register of October 15, 1976.³¹ The current methodology for MUP designation is described in the original regulations.³² The basis for identifying MUPs under the current regulation is a computation of the Index of Medical Under-service (IMU), which is comprised of four components:

1. ratio of primary care physicians to population;
2. infant mortality rate (IMR);
3. percentage of the population which is age 65 and over; and
4. percentage of the population with incomes below the poverty level.^{27,32}

The MUP designation was aimed at populations with “economic barriers (low-income or Medicaid-eligible populations), or cultural and/or linguistic access barriers [now described as limited English proficiency or LEP] to primary medical care services.”³¹ The IMU incorporates the above data for an underserved population group and is strongly rooted within an area of residence such as a county, contiguous counties or a group of census tracts, to obtain a score for the specific underserved population group.³¹

To calculate the MUP, the data from each of the four components is ‘weighted’ and added into the IMU formula.³¹ The ratio of primary care physicians to population translates to a calculation of the ratio of full time equivalent (FTE) primary medical care physicians who treat the requested population group per 1,000 of the number of people in the requested underserved population within a designated area.³¹ The weighted value for poverty is calculated based on the percent of the specified

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population group with incomes at or below 100 percent of the poverty level in the area of residence.³¹ The weighted values for percent of population age 65 and over and the infant mortality rate would be those for the requested segment of the population in the area of residence, if available and statistically significant.³¹

The IMU score ranges from zero to 100. The result gives a standardized score, and the current regulations employ the 1975 median county IMU score of 62 as the threshold value.²⁷ If the sum of the weighted values of the above data gives a score of 62 or below, the population is designated as underserved.³¹

Exceptional MUP Designation

States can request designation for a population group that does not score a 62 or below on the IMU and experiences “unusual local conditions which are a barrier to access to or the availability of personal health services” through the Governor’s Exceptional Medically Underserved Population (EMUP).³¹ To address unique circumstance, the Governor must make the request for designation to the Secretary of HHS in writing together with local officials.³¹ The written recommendation for the designation must “describe in detail the unusual local conditions/access barriers/availability indicators which led to the recommendation for exceptional designation and include any supporting data.”³¹

Attempts to Update the MUP Designation Procedure

There have been two failed attempts to update the MUP designation criteria through the negotiated rulemaking process in 1998 and 2008.^{27,33} Neither proposal mentioned people with I/DD or people with disabilities.³³ HRSA declined to proceed with the published proposed rules because many areas and populations would lose designations, particularly in rural areas that began to merge with urban area over the years since the designation process first began.³³

The most recent attempt to update the MUP designation was mandated by the Affordable Care Act (ACA).³⁴ It directed the Secretary of HHS to establish a negotiated rulemaking process to reexamine the methodology for designating areas and populations that are experiencing medical underservice and/or health professional shortages.²⁷ The Secretary announced the intent to form a negotiated rulemaking committee to develop revised underserved and shortage designation methodologies recognizing the significant challenges of developing shortage methodologies that are fair and equitable; effective in identifying high need areas and populations; and agreeable to the various stakeholder groups and communities.^{1,27} After significant advocacy, the cross disability community secured a representative on the negotiated rulemaking committee (NRC).

According to its mandate, the NRC had to reach 100% consensus. The NRC final report, filed October 31, 2010, did not show consensus. Two of the 28 members filed a minority report.²⁷ No rule has yet been released. The majority report recommended the committee’s MUP designation proposal, which offers applicants the ability to submit an alternative population-specific barrier and/or health status indicator, in lieu of the generally prescribed indicators for these components. Additionally, this proposal provides a flexible local data option for population groups, recognizing that data for the general population of an area may not adequately capture needs of population groups and that data for certain population groups is often non-existent.

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The NRC acknowledged that many populations are widely recognized in national reports, such as Healthy People 2020, as experiencing health disparities.^{27,35} The NRC expects these population groups to include, but are not limited to the following: low income and uninsured; lesbian, gay, bisexual and transgender (LGBT) populations; people with HIV infection; people with mental health, physical, sensory, cognitive, or developmental disabilities; individuals with low English proficiency (LEP); Native Hawaiians; incarcerated populations; and immigrants and refugees. People with I/DD also fall into many of these population groups.²⁷

The flexibility the NRC incorporated into the process also recognized that local data might not be available to determine provider services available to specific population groups. Because of this, it included the possibility that applicants of population groups would need to survey local providers and organizations and groups that represent or support those population groups.

Instead of the current measure of health status of infant mortality, the NRC broadened the health status measure to standard mortality rate (SMR) plus either low birth weight (LBW) or diabetes. The committee added a 'barriers to care' category that requires populations to select and provide data for 2 of the following barriers of their choice:

1. the percent of the population with limited English proficiency (LEP) or Hispanic ethnicity;
2. the percent of the population that is of a non-white racial group (e.g. those who identify as non-white);
3. the population density of the area (whether urban or rural), or the travel time from a frontier or other rural area to the border of a defined urban area;
4. the percent of the population with a physical, mental, or emotional disability*²⁷; or
5. the percentage of the population that is both uninsured and at or below 400 percent of the Federal Poverty level.²⁷

Supporting data should come from nationally maintained data sets available for the population seeking designation, such as the American Community Survey. Applicants can also use local, state, or tribal data if national data is unavailable. Examples of the population-specific local barriers include, but are not limited to, barriers to access resulting from (a) geography, (b) discrimination based on sexual orientation, gender identity, or HIV status or other stigmatization; (c) people with physical, sensory, cognitive, or developmental disabilities; and (d) literacy or culture.²⁷

The NRC also proposed additional new facility designations. The relevant ones for the I/DD population include magnet clinics, safety net providers, and Federal and State Prisons, Youth Detention Centers, and County Jails. The magnet clinic draws patients from long distances seeking culturally sensitive care. A magnet clinic is defined as one where more than 50 percent of encounters are provided by primary care clinicians, to one or two populations groups nationally recognized as experiencing health disparities as outlined above.

* This was chosen the Behavioral Risk Factor Surveillance System (BRFSS) produces data that can be utilized for this purpose. The BRFSS survey question is as follows: Are you limited in any way in any activity because of physical, mental, or emotional problems? 1) Yes; 2) No; 7) Don't Know/Not Sure; 9) Refused. The American Community Survey (ACS) produced by the Census Bureau, will, in 2013 begin reporting data related to those reporting disabilities.²⁷

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Safety net providers are facilities delivering significant percentages of their primary care services to low-income individuals at or below 200 percent of the Federal poverty level; or to individuals who are uninsured, have Medicaid or State Children's Health Insurance Program coverage, or other means-tested public insurance programs.

Under the NRC's recommendations, Federal and State Prisons, Youth Detention Centers, and County Jails, which typically have many resident who are members of the I/DD population, would be able to count all inmates instead of being limited to counting only inmates incarcerated above a certain security level.^{27,36}

Benefits of the MUP Designation & Consequences of Exclusion From Designation

More than 25 government programs within HRSA and other federal agencies require a designation as a MUP to participate in or benefit from "billions of federal resources."²⁷ These programs cover federal funding for health center and public health infrastructure development such as federally qualified health centers (FQHCs).^{27,31} The MUP designation grants eligibility to apply for federal funding to develop and operate Community Health Centers, Migrant Health Centers, health care for the homeless, Federally Qualified Health Centers (FQHCs) and FQHC Look-Alikes.²⁷

The designation for MUP and another closely related designation, Health Profession Shortage Area (HPSA), which covers all FQHCs, are also required for federal programs that fund HRSA's Workforce Development and Training Programs²⁷. HRSA's Bureau of Health Professions administers multiple Public Health Service Grant Programs, which give funding preference to Title VII and VIII training programs for those who work with MUPs.³¹ The Title VII and VIII training programs provide federal funding to train primary care providers, nurses, dentists, mental/behavioral health and other health professionals who work with MUPs.²⁷ HRSA also administers the National Health Service Core (NHSC) scholarships, which provide health profession training, placement, and student loan repayment for students who work in HPSAs.²⁷ Other HRSA scholarship programs are available for disadvantaged students and for Native Hawaiian Health.²⁷

Since MUP and HPSA designation were first required by statute in connection with the NHSC and Community Health Center programs, additional programs have been required by statute to use these designations.¹ For example, the Centers for Medicare and Medicaid Services (CMS) certifies Rural Health Clinics (RHCs) located within rural areas that are HPSAs or MUPs.¹ Further, the CMS Medicare Incentive Program provides higher reimbursement for physician services delivered in HPSAs.¹ CMS also certifies as Federally Qualified Health Centers (FQHCs) organizations that do not receive HRSA grants but serve a MUP and otherwise meet the definition of a Health Center under Section 330 of the PHS Act.¹

The MUP designation allows a variety of federal agencies and state health departments to qualify for J-1 visa waivers for physicians. Under some programs, MUP designation provides for increased reimbursement for funding, and funding preference.²⁷

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Other federal agencies, including the National Institutes of Health, (NIH) concern themselves with MUPs and incorporate the designation into their work. In its Fact Sheet, Health Disparities—Closing the Gap, NIH’s National Institute on Minority Health and Health Disparities refers to its efforts to, among other things, expand research on medically underserved populations. It states as follows:

The NIH is currently 1) expanding the breadth of its research portfolio focused on health disparities experienced by racial and ethnic minorities, the rural and urban poor, and other *medically underserved populations*; 2) conducting population-specific community-based research; 3) enhancing the capacity to conduct health disparities research nationally; 4) recruiting and retaining racial and ethnic minorities and other under-represented groups into the scientific research workforce; 5) establishing health education programs for special populations; and 6) promoting the inclusion of women, minorities and other medically underserved groups in clinical trials.³⁷ (*Emphasis added*)

NIH also targets research and researchers to study and investigate medically underserved populations. Eligibility for grants can lie in one’s commitment to research in health disparities, and knowledge of a “health disparity population,” defined in part as “medically underserved, low socioeconomic populations and rural populations.”³⁷ NIH solicits grants through requests for applications (RFA) that refer to “medically underserved populations.” A current grant announcement for NIH’s Small Business Innovation Research (SBIR) Grant for Development and Translation of Medical Technologies to Reduce Health Disparities states:

The NIH defines health disparities as differences in the incidence, prevalence, morbidity, mortality, and burden of diseases and other adverse health outcomes that exist among specific population groups. These population groups include racial and ethnic minorities (African Americans, American Indians, Alaska Natives, Asian Americans, Hispanic Americans, Native Hawaiians, and other U.S. Pacific Islanders, subpopulations of all of these racial/ethnic groups), socioeconomically disadvantaged individuals, and *medically underserved populations* including individuals residing in rural and urban areas.³⁸ (*Emphasis added*)

A previous grant announcement, Community Participation Research Targeting the Medically Underserved, specifically targeted MUPs “as defined by....HRSA.”³⁹

NIH also provides a Health Disparities Research Loan Repayment Program (LRP) to “recruit and retain highly qualified health professionals to research careers that focus on minority health or other health disparity issues.”⁴⁰ At least half of the awards are made to “health professionals who are members of identified health disparity populations.”⁴⁰ NIH defines “Medically Underserved” on its Health Disparities Research LRP webpage and in its RFA with its own definition together with HRSA’s definition of medically underserved areas.^{40,41} These targeted grants and LRPs support and encourage grantees to develop professional careers in health disparities research with medically underserved populations.³⁷

Individual states use the MUP designation in their own laws to provide additional benefits. For example, the Kansas Primary Care Safety Net Clinic Capital Loan Guar-

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antee Act incorporates the MUP language directly from Section 330 of the PHSA as the criteria to qualify for loans for capitol improvements to safety net clinics.⁴² States also use HRSA's MUP designation in RFAs as criteria to warrant preference for the state's own funding for those who will serve MUPs.^{43,44} Even private foundations and non-governmental organizations (NGOs) such as Susan G. Komen give funding and preferences to fund "medically underserved populations."^{45,46}

Consequences of Exclusion from Designation for the I/DD population

Why does the lack of MUP designation matter to the I/DD population?

Without the MUP designation, the I/DD population loses out on a plethora of programs designed to improve health of populations like I/DD, that experience health disparities, poor health, and lack of access to care. First and foremost, the original purpose of the MUP designation was to respond to the lack of access to preventative and primary health services and to empower communities to solve local access programs and improve health status.²³ As a population excluded from the MUP designation, the I/DD population is excluded from these targeted public health efforts.

As a population excluded from the MUP designation, the I/DD population is excluded from the more than 25 programs within HRSA and other federal agencies that require the designation. Exclusion from these programs mean the I/DD population is excluded from the benefits of "billions of federal resources" for health-related programs for a population that experiences significant health disparities and lack of access to health.^{24,27} Inclusion in these funding opportunities could make a significant difference in the health of the I/DD population.

HRSA's many training and scholarship programs for health professionals that train professionals to work with MUPs could provide an opportunity to train a workforce to study and treat the I/DD population, a population now excluded from the MUP designation.²⁷ A trained population of primary care providers and others health professionals prepared to meet the health needs of people with I/DD could improve the health of the I/DD population, as these training programs are designed to do for other MUP populations. Programs that provide funding preferences to encourage providers to address the unique health needs of specific populations could benefit the I/DD population if they were included. With funding preferences, there is would be an incentive for providers and researchers to study I/DD or cater to or specialize in the health care needs of the I/DD population.

The special medically underserved populations—migratory and seasonal agricultural workers, the homeless, residents of public housing, and Native Hawaiians—can benefit from special clinics designed to meet their unique needs.^{25-27,44} As a population outside the MUP designation, the I/DD population does not have this opportunity for special clinics designed to meet their unique health needs.

The exclusion from the MUP designation causes the I/DD population a significant loss through NIH program requirements. NIH's method to build a research workforce to study health disparities through funding preferences and loan repayment for underserved populations does not include people with I/DD.^{37,40} NIH does not fund research into disability health disparities.⁴ Reality forces researchers to follow the funding. Without funding preferences and loan forgiveness for I/DD health disparities re-

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search, researchers will study other populations that do qualify for funding. The lack of funding for I/DD research into the health disparities this population experiences prevents the development of a research workforce to study the unique health needs of I/DD population—a needed legacy. Further it reinforces a disincentive to study the I/DD population.

The I/DD population also misses out on many opportunities to improve their health via state funded grants and grants from NGOs. States and NGOs also fund services for, and the study of MUPs, as well as training programs to train health professionals in cultural competence, and to meet the health needs of MUPs.^{43,45,46} Unfortunately, as a population not designated as a MUP, the I/DD population is not eligible for these grants.

Designation as a MUP designation would benefit the I/DD population in many ways. In-stead, people with I/DD continue to experience poor health and decreased access to care.

The I/DD Population Should Be Designated as a MUP

The I/DD population experiences significant health disparities, poorer health, and lack access to care.²⁻⁴ Designation as a MUP would help to remedy the health disparities faced by the I/DD populations.

The I/DD population meets a minimum of 3 of 4 of the factors weighted in the current MUP designation formula and will meet the fourth factor as the longevity of the I/DD population increases and public health surveillance of the population improves.^{27,32}

1. Ratio of Primary Care Physicians to Population

In 2004, the President's Committee for People with Intellectual Disabilities reported estimated that seven to eight million Americans of all ages experience some degree of intellectual disability.⁴⁷ Others have relied on these numbers.⁴⁸

The Centers for Disease Control and Prevention (CDC)'s Autism and Developmental Disabilities Monitoring (ADDM) network estimated that, as of 2010, approximately one in 68 children living in the 11 sites it surveyed either had an autism spectrum diagnosis or would qualify for one based on available medical records.⁵¹ A landmark study in the United Kingdom found the prevalence of autism in the adult population to be similar to that found in children.⁵¹

Despite the size of the population of people with I/DD, few primary care providers are trained to treat the I/DD population. Researchers surveyed over 2,500 respondents, including U.S. medical and dental school deans, U.S. medical and dental residency directors, U.S. medical students, and U.S. advocacy and patient care groups.⁸ They found that on average in the U.S., a person with ID would have to contact 50 doctors before finding one with specific training and experience to treat people with ID.⁸ The survey also showed that 81% of medical students report receiving no clinical training for treating patients with ID and 66% report receiving insufficient classroom instruction.⁸ Over half of medical and dental school deans report that their graduates are not competent to treat people with ID.⁸

Designation as a MUP would help to remedy the health disparities faced by the I/DD populations.

Physicians also are often unfamiliar with autism in children and adults. It is not unusual for adults to receive an autism diagnosis for the first time as adults after seeking answers for several years.^{52,53} A survey of general practitioners in the National Health Service in the Bath region of the United Kingdom, found medical clinics were only aware of one autistic adult out of a total population of 98,000 people.⁵⁴

A survey of primary care physicians in Connecticut, found that physicians who reported they received no training during their ongoing professional education, medical residency, or continuing medical education about caring for autistic adults were more likely to report that they did not treat autistic adults: 72.4% of that group compared to 28.9% of those who reported having some training in the care of autistic adults.¹¹ Over half of the physicians stated they would like more training in caring for autistic adults.¹¹ Half also stated they would also like training on other developmental disabilities such as Down syndrome, cerebral palsy, and ADD/ADHD.¹¹

This lack of training and lack of competent providers to treat people with ID/DD translates to a “real world” lack of access to care. In a letter to the NRC, Dr. Matthew Holder, a developmental medicine physician, told the NRC that he runs a medical and dental clinic that serves the I/DD adult population in Kentucky.⁵⁵ He reported that he serves over 1000 people from 45 counties in Kentucky.⁵⁵ People travel from miles away to see him because he is the only one in Kentucky trained to treat the I/DD population.⁵⁵ Dr. Holder points out that since this population is so underserved, few are likely to live into their 60's.⁵⁵

The American Academy of Developmental Medicine and Dentistry (AADMD) Consensus Statement on Health Disparities for Persons with Neurodevelopmental Disorders and Intellectual Disabilities stresses that individuals in the I/DD population consistently face challenges finding clinicians trained to treat them.⁵⁶ It notes the majority of physicians and dentists have limited knowledge of the health and psychosocial needs of this population primarily due to a lack of exposure and training.⁵⁶ Clinicians often harbor limiting attitudes toward individuals with I/DD and this contributes to the stigmatization and marginalization that often defines their health care experience.⁵⁶

The Institute of Medicine (IOM) found that lack of provider education and disability awareness needed to counter disability stereotypes and the misconceptions held by health care providers is one of the most significant barriers to care.⁵⁷ Based in part on the limited number of competent providers trained to meet the unique needs of the I/DD population, the American Medical Association (AMA) voted to support designating the population of individuals with I/DD as a MUP.^{48,58}

2. Infant Mortality Rate

Infant mortality rates (IMR) for the I/DD population far exceed the IMR for the non-disabled population. A study of 1305 infants born in Tennessee with Down syndrome from 1990 to 2006 showed that 97 died within the first year, for a mortality rate of 74 per 1000.¹⁴ Premature babies, who by the nature of the premature birth experience developmental disabilities, also have a high mortality rate.¹⁶ Developmental disabilities were the fifth leading cause of nontraumatic death for children between 1 and 14 years of age.¹⁵ When researchers used a multiple-cause approach to define developmental disability-related deaths (i.e. when considering contributing as well as underlying cause), the number of these deaths nearly doubled.¹⁵ Increased mortality often occurred as the result of the cause of the developmental disability (ie. genetic syndrome), multiple co-occurring disabilities, or secondary conditions such as asthma, seizures, infections or heart conditions.⁷

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3. Percentage of the Population with Incomes Below the Poverty Level

People with disabilities are grossly overrepresented among those who live in poverty.⁵⁹ A common finding in population-based research in most developed nations is the substantial exposure to poverty among persons with I/DD.^{59,60} According to U.S. Census data, 28.6% of individuals with severe disabilities—a category that includes the I/DD population—live in poverty.¹² According to American Community Survey data, more than a third—34.2% of non-institutionalized persons aged 21 to 64 years with a cognitive disability, in the United States lived below the poverty line in 2011.⁶¹ American Community Survey data shows that only 11% of non-institutionalized persons aged 21-64 years with a cognitive disability in the United States were employed full-time/full-year in 2011.⁶¹

A study by the National Autistic Society (UK) (NAS) reports that only 15% of autistic adults are employed, though most are willing to work.⁶² According to the NAS, this condemns many autistic adults to a life of poverty.⁶³ In a Canadian study, 13.9% of autistic adults surveyed were employed full-time and 6.1% were employed part-time.⁶⁴

4. Percentage of the Population Age 65 and Over

While the further data is needed in this area, it is clear that adults with I/DD are experiencing increased longevity.⁶⁵ Although individual older adults with I/DD still generally die at an earlier age than adults in the general population—average age at death: 66.1 years—many adults with I/DD live as long as people in the non-disabled population.¹⁷ Based on the 2010 Census, experts estimate 850,600 people with I/DD age 60 and older live in the community.⁶⁶ This number does not include those who live in institutions. The projected number of older persons with I/DD is expected to double by 2020.⁶⁵ By 2030 their numbers will reach 1.4 million due to increasing life expectancy and the aging baby boomer generation.⁶⁶

An Australian study of trends in survival profiles of people with intellectual disability reports an average age of death of 71 for people with mild and moderate intellectual impairment absent other chronic health conditions.⁶⁷ Data show an increase in longevity of individuals with Down Syndrome from 38 years in the 1960's to 55.8 in the 1970s. One study found that 25% of individuals with Down Syndrome living between 57 and 62 years with the oldest person reaching age 73.⁶⁸

Information is beginning to emerge on the aging-related long term effects and interactions of a number of neurodevelopmental conditions within the I/DD family, including autism, cerebral palsy, Down syndrome, fragile X syndrome, Prader-Willi syndrome, spina bifida, and Williams syndrome.⁶⁶ The bottom line is that people with I/DD are living longer, and joining the population of people age 65 and over, in increasing numbers.

The Geographic Barrier to MUP Designation

The proposed designation suggested by the NRC mentions disabilities for the first time and considers factors that make it easier for populations of people with disabilities to get a MUP designation.³¹ However, the issue of geography still makes it impossible for the I/DD population to get a MUP designation. Though the I/DD population meets at least three of the four criteria for MUP designation and will likely meet the

...more than a third—34.2% of non-institutionalized persons aged 21 to 64 years with a cognitive disability in the United States lived below the poverty line in 2011.

fourth in the future, it can never meet the “geographic area” requirements of MUP designation. Despite the data that supports a MUP designation, the I/DD population cannot qualify for the designation because they do not live in the same residential area. This presents a dilemma for individuals with I/DD. After more than 40 years of successful advocacy to end forced segregated living in institutions, and enact disability legislation protecting their rights to live where they want to live, the I/DD population is in effect told that if they want the MUP designation, they must live in I/DD ghettos.

Living in I/DD ghettos is against public policy.²⁰ In *Olmstead v. LC*, the United States Supreme Court held that finding that the unjustified institutional isolation of people with disabilities violated the anti-discrimination mandates of the Americans with Disabilities Act of 1990 (ADA).^{69,70} This Court noted that the history of institutionalization was a means of segregating and demeaning persons with serious disabilities.⁷⁰ The U.S. Department of Housing and Urban Development (HUD) recently affirmed this position when it said “the promise of *Olmstead* is that individuals with disabilities be given meaningful opportunities to live, work, and receive services in integrated settings.”⁷¹

Though the federal government is not subject to the ADA, it is subject to the Rehabilitation Act of 1973;⁷² Claims under the ADA and the Rehabilitation Act are generally treated the same.⁷¹ The unjustified segregation called for to qualify for a MUP designation is discriminatory segregation, demeaning to people with I/DD, and in violation of the spirit and intent of *Olmstead*, the ADA and the Rehabilitation Act. Forced segregation in housing also violates the Fair Housing Act.⁷³ Forced segregated housing even violated the United Nations Conventions on the Rights of People with Disabilities (CRPD). Title 19 of the CRPD states that persons with disabilities must be able to live independently, be included in the community, and to choose where and with whom to live.⁷⁴

A lot of effort has gone into integrating people with I/DD into community living. Therefore, ‘the government’ should recognize that it is not in the best interest of anyone for people with I/DD to live in the same locale. At some point, ‘the government’ should focus on the health needs of the I/DD population and see the legal inconsistencies in its focus on people living in the same locale. Like other members of society, people with I/DD live in rural and urban areas.^{4,10} Unlike other members of society, people with I/DD experience lack of access to care, high infant mortality, poverty, and health disparities as a population—in spite of where they live.⁷⁵

The I/DD Population Experiences Significant Health Disparities

Two Surgeons General Reports and a report of the National Council on Disabilities document that as a population, people with I/DD experience significant health disparities, poorer health, and lack access to care.²⁴ Public health survey data and the peer-reviewed literature both support the existence of significant health disparities in the I/DD population.⁷⁶ Examples of these health disparities appear below.

HEALTH STATUS: A study of health disparities comparing individuals with I/DD with those without disabilities in North Carolina provides an comprehensive overview of the health disparities the I/DD population experiences.⁷⁷ Though people with I/DD are living longer, they do not receive the same care, they do not live as long, and they do not have the same health status as people without disabilities.⁷⁸ People with I/DD were significantly more likely to be in fair or poor health than adults without disabilities.^{5,77}

After more than 40 years of successful advocacy to end forced segregated living in institutions... the I/DD population is in effect told that if they want the MUP designation, they must live in I/DD ghettos.

PHYSICAL ACTIVITY: People with I/DD tend to live sedentary lives.⁷⁹ Individuals with I/DD were significantly more likely to have had no exercise in the previous month than those in the No Disability group.⁷⁷ According to parental report, children with autism engaged in fewer physical activities and for less time than children without autism.⁸⁰ Decreased physical activity and sedentary lifestyle puts the I/DD population at risk for obesity and osteoporosis.

CHRONIC CONDITIONS: Individuals with I/DD experienced a higher incidence of cardiovascular disease, chronic pain, and diabetes than people without disabilities.⁷⁷ A Scottish study reported that individuals with I/DD commonly experienced epilepsy, gastro-oesophageal reflux disorder, and osteoporosis among other conditions.⁷⁸ People with I/DD are less likely to have their cancer detected early or have their chronic conditions managed properly.⁸¹

Health Care Utilization

WOMEN'S HEALTH SCREENING Women with I/DD were significantly less likely to have had routine breast and cervical cancer screenings than women without disabilities.⁶⁰ 11.5% of women with I/DD reportedly had never visited a gynecologist. Women with I/DD were significantly less likely than women without disabilities to have had a mammogram.⁶⁰ Although women in the U.S. are advised to have mammograms every one or two years beginning at age 40, 26.8% of women with I/DD age 40 or older in this study reportedly had never had a mammogram.⁷⁷

ORAL HEALTH People with I/DD experience poor dental hygiene, obvious signs of tooth decay and significantly more mouth pain than adults without disabilities.^{8,60} Individuals with I/DD were more likely than those in the No Disability group not to have had their teeth cleaned in the past five years or never to have had their teeth cleaned.⁷⁷

MORTALITY AND ACCESS TO CARE issues were discussed previously in this policy brief. (See above)

While some claim there is not as much health disparity data for disability populations as there for populations based on race or ethnicity, there is enough data, as seen throughout this policy brief, to show significant health disparities exist. While data is captured in a wide range of population-specific data sets across the country, national surveys of population health are limited in their ability to describe even basic health indicators in people with I/DD.³⁶ There have been issues with definitions of I/DD and questions on public health surveys, leaving some data gaps.⁸² For example, the question regarding difficulty learning was replaced with another question; That data is no longer collected.⁸³ Where data is collected, individuals in institutions or group living situations are not counted in these population surveys, leaving out many individuals with I/DD. One expert points out that the data is collected in many different databases, and describes the data as “lacking clarity.”³⁶

Experts recommend developing a common definition with input from all stakeholders to compile and synthesize the existing knowledge base.^{36,81} Using that data, they recommend piloting state or regional demonstrations projects to find multiple approaches for effective surveillance methods to survey people with I/DD and develop approaches to expand effective national surveillance, which may include new tools or population-based surveys. This would insure necessary I/DD specific data going forward to further and continue to support MUP designation through federal or state efforts.

Public health survey data and the peer-reviewed literature both support the existence of significant health disparities in the I/DD population.

Recommendations

Effective action to achieve a MUP designation will require steps on the part of multiple stakeholders. The evidence outlined in this policy brief suggests the following possible key actions to achieve MUP status and begin to address health disparities people with I/DD experience:

Federal Legislative Action

Congress should designate the I/DD population as a MUP. The I/DD population meets the three criteria for MUP designation and will eventually meet the fourth with time and better data collection and public health surveillance. As explained in this policy brief, since I/DD population can never meet the geographic burden required for the MUP designation, advocacy in the federal arena should focus on urging Congress to put the I/DD population in the ‘special medically underserved populations’ category, together with migratory and seasonal agricultural workers, the homeless, and residents of public housing. Like these other ‘special medically underserved populations,’ the I/DD population experiences significant unemployment and underemployment, poverty, health disparities, poorer health and health outcomes, and lack of access to care.

State Action by Governors

Advocates should urge states to act. As explained in this policy brief, the Public Health Services Act provides an exception to the geographic requirement for HRSA’s MUP designation for populations that experience significant barriers but do not meet the criteria—the Governor’s Exceptional Medically Underserved Population (EMUP). This policy brief outlines the significant barriers to care experienced by the population of individuals with I/DD, and these barriers occur among the entire population in every state. Advocates can work state by state with local and state health departments and governors to encourage them to work together to seek the permissible EMUP designation from the Secretary of HHS available under 42 USCS § 254b(b)(3)(D) for the I/DD population in their states.²¹ The request would be based on the lack of trained primary care providers in the state available to treat the population of people with I/DD, the health disparities experienced by individuals with I/DD in the state, and other barriers to care that might be specific to that state. (i.e. rural, frontier areas).

Advocate for Better Data Collection and Public Health Surveillance

Stakeholders must agree on common terminology and definitions of I/DD, and methods of surveillance and data collection. The definitions of I/DD have long been a concern. Since the public health surveys removed the questions on difficulty learning, there is a concern about whether the proper data is being collected. As explained in this policy brief, a plethora of data exists to support the depth and breath of health disparities faced by people with I/DD. Though this data exists, the changing questions and absence of I/DD data collection in population surveys threatens future reliable collection of health data for the population of individuals with I/DD. Advocates should work with the Centers for Disease Control (CDC) and other stakeholders to explore alternative way to collect the public health data, since the current questions do not specify data for the I/DD population. Advocates should also work with the Census Bureau in collaboration with the deaf community so that people with I/DD who are nonverbal or

...advocacy in the federal arena should focus on urging Congress to put the I/DD population in the ‘special medically underserved populations’ category...

have limited verbal skills fall under the category of limited English proficiency (LEP). They define LEP for data collection purposes, and LEP carries certain benefits with the designation as outlined in this policy brief.

Advocate for the Role of I/DD in Society & Healthcare

Stakeholders should continue to work together on strategies that stress the competence of people with I/DD, while advocating for the needs of the population as a MUP. People with I/DD must be regarded as valued contributing members of our democratic society, and stakeholders in their own health care⁸⁴. The health of individuals with I/DD must be viewed in the same way policy makers' view the health needs of other populations marginalized throughout history, many of whom readily qualify as MUPs and health disparate populations.

Advocate for Acceptance of the NRC's Recommendations

The self-advocates, I/DD advocates, researchers, and health care providers should encourage HRSA to release the new rules as recommended by the NRC. As explained in this policy brief, the rule did not remove the geographic requirement. That is in the law and not something the NRC could do. However, the NRC did recommend adding people with disabilities to several sections of the rule so the barriers to care faced by people with I/DD would be considered in the rules. It also recommended new facility designations and/or rule changes that would benefit people with I/DD including the establishment of magnet clinics, safety net providers, and expanded coverage in Federal and State Prisons, Youth Detention Centers, and County Jails.

Strengthen the Workforce of Healthcare Providers to Treat the I/DD Population

Advocates, researchers, self-advocates, service providers, health care providers, public health practitioners, administrators, federal agencies, and disability organizations must work together to advocate for the following:

1. Recognition of I/DD as a health disparate population with unmet health needs, including recognition by NIH and all federally agencies so that more research opportunities will be available for health disparities, quality of life, and participatory action research. We have the data but the advocacy to continue to collect the data and accept the data we have needs to be done by all stakeholders to achieve these results.
2. Recognition of I/DD as a vulnerable or disadvantaged population, an under-served group, and a population subject to health inequity and health disparities by the Office of Minority Health, NIH, and all other federal agencies. There are not necessarily formal definitions for all of these terms but they appear in federal and state rules and laws and with them come benefits in research, programs, and educational opportunities.
3. Establishment of the discipline of Developmental Medicine and Dentistry as primary care providers, with HRSA support for residencies, loan forgiveness, training programs to train primary care providers, including nurse practitioners and physician assistants, and financial incentives (grants) for curriculum development, and

Stakeholders must agree on common terminology and definitions of I/DD, and methods of surveillance and data collection.

the development of continuing medical education for primary care providers to meet the health care needs of people with I/DD.

4. Development of best practice guidelines for prevention, promotion, and treatment of the health care needs of people with I/DD;
5. Establishment of guidelines of the population health needs of the I/DD population for local and state health departments, so that individuals with I/DD will be included in public health efforts at the local and state level.
6. Reimbursement formulas developed by all payors, private, Medicare, and Medicaid that reflects the time and skills needed to meet the health needs of the population of people with I/DD.
7. Inclusion of I/DD knowledge, education, programs, and training in certification programs such as the Joint Commission, and state licensure programs for health providers.

Conclusion

We do not need more reports or studies to prove the I/DD population experiences significant barriers to health care. More than enough evidence exists to document the health disparities, poorer health, poverty, unemployment, and lack of access to properly trained providers that the I/DD population experience daily. These barriers and others leave individuals with I/DD as a population with many unmet health needs. MUP designation is a significant step to begin to address these unmet health needs in earnest. Since MUP designation in its current form and proposed future form places a geographic barrier to I/DD population's MUP designation, advocates must take action to assure eligibility in other ways. Advocates must work together with multiple stakeholders to make MUP status a reality for individuals with I/DD through policy and legislative changes. With MUP status, people with I/DD become officially recognized stakeholders in their own health care, entitled to concrete actions to decrease their health disparities, improve their health, and reduce barriers to their health care.

People with I/DD must be regarded as valued contributing members of our democratic society, and stakeholders in their own health care.

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