Designating People with Intellectual and Developmental Disabilities as a Medically Underserved Population: How to Move Policy Forward

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Learning Objectives

- At the end of this presentations attendees should be able to:
  - Set a goal of MUP designation for the ID/ DD population
  - Create a logical and workable course to take to achieve the change to MUP designation, according to the requirement found within the relevant laws and policies.

What is MUP?

- Congress created the designation "medically underserved population"[1] (MUP) to improve public health using a formula that weighs a population's
  - lack of primary care providers
  - experience with poverty
  - increased infant mortality, and
  - percentage of people over the age of 65.[2]

What Are The Benefits of MUP Designation?

- More than 25 federal government programs require an MUP designation to participate in, or benefit from billions of federal dollars.

MUP Designation Benefits 2

- The programs that use the MUP designation fund health centers and public health infrastructure, such as federally qualified health centers (FQHCs). State agencies, and some private foundations use the designation to award grants, scholarships, and research funding.

Defining an MUP

- To identify MUPs under the current regs is a computation of the Index of Medical Under-service (IMU), comprised of 4 components:
  1. ratio of primary care physicians to population;
  2. infant mortality rate (IMR);
  3. % of the population which is age 65 and over and
  4. % of the population with incomes below the poverty level. [2,3]

How MUP Works #1

- The MUP designation was aimed at populations with “economic barriers (low-income or Medicaid-eligible populations), or cultural and/or linguistic access barriers [now de-scribed as limited English proficiency or LEP] to primary medical care services”

How MUP Works #2

- The IMU (Index of Medical Under-service) incorporates the 4 factor 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.[11]

How MUP Works #3

- To calculate the MUP,
  - the data from each of the four components, as applied to a specified population in a specific geographic area, are 'weighted'
  - and added into the IMU formula.

How MUP Works #4

- The result gives a standardized score.
- If the sum of the weighted values of the above data gives a score of 62 or below, the population is designated as underserved.

MUP & ID/DD: Problem

- The federal government defines MUP in terms of groups or populations of people who occupy the same neighborhood, census tract or geographic area.
- This puts people with intellectual & develop-mental disabilities (I/DD) in a Catch-22.[4]

MUP & ID/DD: Problem

- As a population, people with I/DD experience
  - a lack of primary care providers[7]
  - significant rates of poverty[8]
  - increased infant mortality,[9] and
  - an aging population[11]

MUP & ID/DD: Problem

- However, the I/DD population
  - can never meet the MUP designation standard because
  - they do not live in segregated communities.[4]

MUP & ID/DD: Problem

- This means people with I/DD,
  - now woven into the fabric of our communities,
  - cannot benefit from what other medically underserved populations receive to remedy their health disparities and lack of access to health care.[4]

Possible Solutions – Alternative #1

- There are 3 Alternatives.
- The first: Policy Changes:
  - Update to the MUP Definition
  - A negotiated rulemaking committee met for 14 months to update the definition but did not get sufficient consensus.

Alternative #1 Policy Change

- The report the Committee submitted
  - recommended adding “barriers to care” to the MUP designation criteria and include “the % of the population with a physical, mental, or emotional disability” as one criteria.” [3]
    - Nothing happened since 2011 (submission date)[3]
    - This would be one of several failed attempts to update the rule.

Alternative #2 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).[11]

Alternative #2 Exceptional MUP Designation

- To address unique circumstance, the Governor must make the request for designation to the Secretary of HHS in writing together with local officials.
- 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." [11]

Alternative #3 Legislative Change

- Congress could amend the Public Health Services Act to make the I/DD population a "special medically underserved population," like "migratory and seasonal agricultural workers, the homeless, and residents of public housing" are currently designated.[12]

Which is the Best Course to Take?

- Both public policy and current laws (ADA, Fair Housing Act, Rehab Act) require that people with disabilities play an inclusive role in society.

Which is the Best Course to Take?

- Since the MUP process focuses on where people live, people with I/DD can never benefit from MUP designation in its current form, since disability ghettos violate these laws.
  - This is in spite of the fact that the I/DD population meets all of the individual criteria required for MUP designation.

Which is the Best Course to Take?

- While the governor's exception is a possible route, the best way for the I/DD population to benefit from the MUP designation is through legislative change and designation as a "special medically underserved population."

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