Designating People with Intellectual and Developmental Disabilities a Medically Underserved Population
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Problem:
• People with Intellectual and Developmental Disabilities (IDD) have numerous well-described health disparities related to their underlying conditions and functional limitations (see Surgeon General’s Report, 2002; CDC, 2009; Special Olympics Healthy Athletes Program; AADMD website)
• There are about 10 million people with IDD and related neurodevelopmental disabilities in the US, relatively evenly dispersed and now mainly served in integrated community settings
  o NY State OPWDD serves about 130,000, 7-10,000 in Western NY Region 1, but an estimated 2/3 of people with IDD are not served by the OPWDD system)
• Health and Oral Health providers receive limited training in the special needs of people with IDD related to common problems and delivery of services
• Disincentives for health and oral health providers to serve people with IDD include:
  o Extra time required
  o Needed physical, behavioral, and communication accessibility adaptations
  o Limited ability for individuals to self-direct/self-manage health care
  o Increased administrative/paperwork demands
  o Medicaid reimbursement

Result:
• Difficulty transitioning from pediatric to adult health/oral health care
• Neglected primary care
  o Health Protection (immunization, routine screening, smoking cessation)
  o Inadequate screening for Hearing (21%) and Vision (up to 67%) problems
  o Blood tests (medication levels, cholesterol, blood sugar, hepatitis)
  o Weight monitoring and management
  o Gynecological care
• Increased emergency room use, hospital length of stay and early readmission
• Increased use of higher cost services (e.g., dental work under general anesthesia)
• Increased incidence of preventable complications

Response: Medically Underserved Population (MUP) Designation:
• Supported by AMA, ADA, and other professional organizations
• Outside HRSA model because of geographic diversity
• Supports People with IDD and Families
  o Improved access to appropriate care
  o Improved coordination across systems
• Supports Providers
  o Loan forgiveness
  o Training
  o Tools
  o Preferred Provider reimbursement
• Supports Health Systems
  o Identify based on ICD code—encourages coding which in turn facilitates care
  o Accountable Care Organizations
  o Community Health Centers
• Supports Governmental Goals
  o Medicaid/Medicare cost containment
  o Managed care models—data to improve quality
  o Supports community inclusion, employment, participation