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Adult Medicaid Enrollees with Intellectual and Developmental Disabilities (I/DD): Access to Behavioral Health Services

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Medicaid and CHIP Payment and Access Commission

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Background

I/DD and Behavioral Health

- In the 2025-2026 analytic cycle, MACPAC conducted an analysis of behavioral health spending and utilization using 2023 data
- This analysis uncovered notable findings specific to people with I/DD, including that behavioral health services accounted for the majority of Medicaid spending for:
  - Adults with I/DD conditions (61.3 percent)
  - Adults with co-occurring mental health and I/DD conditions (63.6 percent)
- Continuing this work, we will conduct a quantitative and qualitative analysis to understand how adults age 19-64 with I/DD receive and use behavioral health services in Medicaid and the barriers they may face to accessing those services
  - Beginning with literature review and scan of federal policy

Defining I/DD and Behavioral Health

- I/DD are conditions that are typically present at birth and affect a person's physical, intellectual, or emotional development
  - Examples include cerebral palsy, Down syndrome, autism spectrum disorders
  - Definitions of I/DD may differ depending on the source or program
  - Recent analysis from the National Residential Information Systems Project (RISP) estimates about 8.6 million people in the United States had an intellectual or developmental disability, including about 2.2 million adults
- Behavioral health includes mental health and substance use disorders
  - Mental health conditions may include anxiety disorders, mood disorders, personality disorders, and schizophrenia
  - Substance use disorder conditions include opioid use disorder, alcohol use disorder, and other drug use disorders

Literature Review Findings

Data Sources

- Data sources on adults with I/DD are limited
  - Health surveys often exclude information about I/DD

- **National Core Indicators – Intellectual and Developmental Disabilities**
  - 81 percent of respondents lived in a metropolitan area
  - 82 percent had an intellectual disability diagnosis
  - 30 percent had autism spectrum disorder diagnosis
  - 60 percent male
  - 65 percent white
  - 23 percent age 55+
  - 49 percent had Medicare coverage
  - 49 percent lived in parent or relative's home

- **National Survey on Health and Disability**
  - 54.7 percent of respondents with I/DD age 18-64 reported having some Medicaid coverage
  - 66.7 percent with Medicaid coverage needed help at home due to health or disability, compared to fewer than half with private-only coverage
- **RISP**
  - 1.4 million received LTSS from state I/DD agencies in 2021
  - Vast majority lived outside institutions; 63 percent in the home of a family member

Health Conditions and Expenditures

- Adults with I/DD experience higher rates of chronic conditions
  - Among Medicaid enrollees age 19-64 with I/DD, 67 percent have a chronic condition, vs. 42 percent of enrollees without I/DD
- Adults with I/DD have higher rates of behavioral health conditions
  - Medicaid enrollees age 19-64 with I/DD were 1.6 times more likely to be diagnosed with a behavioral health condition than those without I/DD
  - Higher prevalence of anxiety and depression, more frequent and severe symptoms, more psychiatric medication use, more cost-related barriers to therapy
- Adults with I/DD have higher health care spending
  - Per enrollee Medicaid spending for people with I/DD almost four times higher than per enrollee spending among all Medicaid enrollees ($24,974 versus $6,582)
  - For people with both I/DD and a behavioral health diagnosis, this gap was even wider ($34,604 versus $6,582)

Access Challenges

- People with I/DD face barriers to accessing behavioral health care
  - Delivery systems for I/DD services and behavioral health services are often separate, with different eligibility, funding, and regulatory frameworks
  - Inadequate transportation, long wait times
- Challenges at the provider level can prevent access
  - Behavioral health conditions in people with I/DD can be difficult to diagnose
  - Limited provider training and expertise on I/DD
    - Diagnostic overshadowing: providers may ascribe behaviors or symptoms to an individual's I/DD rather than to a potential behavioral health condition
  - Reliance on pharmacological treatments

Federal Policy Scan Findings

Eligibility for Medicaid and LTSS

- Federal law does not specify a single, I/DD-specific Medicaid eligibility pathway applicable to all adults with I/DD
- Many adults with I/DD are eligible for LTSS in an institution or through home- and community-based services (HCBS)
  - Federal policy gives states flexibility for establishing eligibility criteria for LTSS

Among adults age 19-64 with I/DD in Medicaid…

76% qualify through a disability-related pathway

56% use LTSS

92% of LTSS users use HCBS

Notes: I/DD is intellectual and developmental disabilities. LTSS is long-term services and supports. HCBS is home- and community-based services.
Source: KFF analysis of the T-MSIS Research Identifiable Files, 2021

Evaluation of Behavioral Health Needs

- At application, federal policy generally only requires states to evaluate behavioral health needs of adults with I/DD who qualify through disability-related pathways or receive LTSS
- Once enrolled, there are few broadly applicable federal requirements for adults with I/DD not enrolled in LTSS to receive behavioral health evaluations
  - These adults may receive behavioral health evaluations if they are covered through other provisions, such as:
    - Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit for adults under age 21
    - Alternative Benefit Plans (ABPs)
    - Optional state plan benefits

Evaluation of Behavioral Health Needs: LTSS

- Adults with I/DD receiving HCBS must receive a functional needs assessment before enrolling in services and at least annually thereafter
- Requirements for evaluating behavioral health needs in functional needs assessments vary by HCBS authority and by state
  - Section 1915(i) explicitly requires assessments to evaluate behavioral health care and support needs, while Sections 1915(c) and 1915(k) do not (42 CFR 441.720(a)(4))
  - States have flexibility when designing assessment tools

Coverage of Behavioral Health Treatments

- While there are some federal requirements for mandatory coverage of behavioral health services in Medicaid for adults with I/DD, many services are covered as optional services under state plans
- Adults with I/DD receiving HCBS may receive behavioral health services included in a person-centered service plan
  - These adults may also receive services through the state plan
  - States may develop tailored HCBS programs to cover additional behavioral health services, including behavioral supports, for adults with I/DD

Care Coordination for Co-Occurring Conditions

- Federal policy does not contain broadly applicable requirements to coordinate care for adults with co-occurring I/DD and behavioral health conditions
- Certain federal models may promote care coordination for adults with co-occurring conditions
  - Federally Qualified Health Centers (FQHCs)
- States have used flexibilities in federal policy to develop models for care coordination
  - Arkansas: Provider-Led Arkansas Shared Savings Entity (PASSE) under Sections 1915(b), 1915(c), and 1915(i) authorities

Next Steps

Discussion

- In your experience, to what extent are people with I/DD evaluated for behavioral health needs?
  - Could states benefit from additional federal requirements or guidance?
- What elements of care coordination do you think are most important for adults with I/DD who also need behavioral health services?
- Which potential areas for additional policy analysis should we prioritize? For example, we might consider exploring the following areas:
  - Differences in functional needs assessments and person-centered planning processes for adults with I/DD and behavioral health conditions across states and HCBS authorities
  - Use of managed LTSS for adults with I/DD and behavioral health needs
  - State models of care coordination for adults with co-occurring I/DD and behavioral health conditions

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OCTOBER MEETING

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