



Overview of Health Insurance for People with Intellectual Disabilities

Introduction

People with Intellectual Disability (ID) receive health care through a variety of sources in the United States. While most people with ID are enrolled in Medicaid, other important sources of coverage include Medicare and private insurance. This overview provides a background on sources of health care coverage for people with ID and where they receive services.

History

The history of health and health care for people with ID is shaped by our nation's history of institutionalization and discrimination. Beginning in the mid-19th and early 20th centuries, people with ID were often institutionalized in large state-operated facilities, or otherwise kept isolated from mainstream society. The creation of public special education, downsizing and closure of state operated facilities, and the disability rights movement during the late 20th century transformed the health care system to one that largely supports people with ID in their communities, increasingly in their own homes and with family or friends. As individuals with ID are more often supported in their homes and communities, they increasingly receive their acute and primary health care services in the mainstream health care delivery system.

While deinstitutionalization has overall improved the health and life expectancy of people with ID, disparities remain. Advancements in community-based services have improved quality of life for people with ID, but the provision of adequate health care services remains a concern. Research has found that individuals living in more restrictive environments, including community-based group homes, have a higher likelihood of receiving preventive exams than those living on their own or with family or friends.¹

Population health data reflect continued disparities. Adults with IDD are at greater risk of hearing and vision impairments, cardiovascular disease, obesity, seizures, mental health and behavior problems, poor oral health, and poor general fitness. According to the National Council on Disability (NCD), people with intellectual and developmental

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disabilities (IDD)¹ face a “constellation of health and health care disparities, including inadequate health and wellness promotion and inconsistent access to high-quality health care services.” NCD notes that the rate of adults with IDD face significantly higher rates of obesity (35%) than adults without IDD (21%). The Autistic Self-Advocacy Network (ASAN) notes that individuals with IDD experience higher instances of cardiovascular disease, chronic pain, and diabetes than people without disabilities. ASAN also describes research finding that people with IDD tend to live sedentary lives, being much more likely to report engaging in no exercise than adults without disabilities, a trend that begins in childhood.

Disparities in health outcomes stem in part from disparities in access to health services including:

- Lack of cognitively accessible materialⁱⁱ which contributes to low health literacy among people with IDⁱⁱⁱ
- Low numbers of primary care providers with training or experience in serving people with ID. 81% of medical students report no clinical training on treating patients with ID and 66% report insufficient classroom instruction^{iv}
- Pervasive stereotypes or misinformation about people with ID, including that they feel less pain, do not engage in sexual activity, or cannot (or should not) live long and healthy lives^v
- Negative past experiences with health care providers, resulting in people with ID being less likely to seek care^{vi}
- Inadequate supports for care transition from pediatric to adult health care systems^{vii}
- Insurance payments that do not consider additional time required, both appointment times and additional care coordination needed by people with ID^{viii}
- Narrow networks that do not include providers with experience serving people with ID^{ix}
- Lack of access to dental care, contributing to health problems stemming from poor oral health^x

Insurance Coverage for People with Intellectual Disability

People with ID receive insurance through three primary sources: Medicaid, Medicare, and private insurance, however data on actual coverage rates is limited.² Data collected on coverage sources for people with ID is generally limited to those who are eligible for coverage on the basis of their disability. Nearly all studies recognize that many more people with ID are eligible through other eligibility pathways, such as income or age, and that more people with Medicare and Medicaid are enrolled in the program than eligibility data suggests. As a result, advocacy efforts to improve health care access and outcomes for people with ID cannot be limited to those eligible on the basis of their disability, or to one form of coverage.

¹ While this paper focuses on people with intellectual disability, nearly all research, publication, and public programs describe people with intellectual and developmental disabilities together. In those cases, the abbreviation IDD will be used.

² Other forms of insurance include TRICARE (health coverage for active duty military members and their families) and the Veterans Administration health care system. This paper will focus on Medicare, Medicaid, and private coverage as the most common.

Medicaid

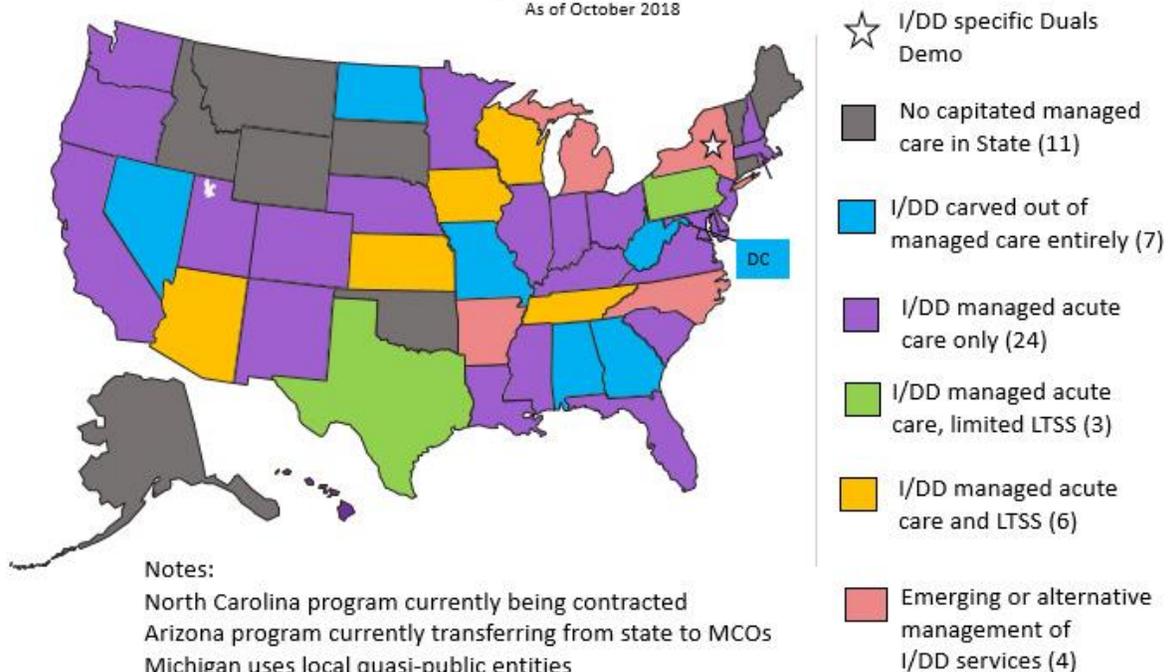
Medicaid is a joint federal-state program for people with low incomes and people with disabilities. The federal Centers for Medicare and Medicaid Services (CMS) set broad program parameters, including mandatory and optional benefits. States determine coverage guidelines and reimbursement structures for these benefits. According to the NCD, Medicaid covers 1.7 million people with ID. Medicaid is the primary payer of long-term services and supports (LTSS); LTSS is not covered by Medicare and almost no private health insurance plans cover any form of LTSS.

People with ID become eligible for Medicaid primarily through their eligibility for Supplemental Security Income (SSI) payments. Individuals with disabilities are eligible for SSI by virtue of significant functional limitations and very low income or assets.

Since the 1980's states have increasingly engaged in the privatization of Medicaid programs by contracting with private Managed Care Organizations (MCOs), or similar arrangements.³ Under these arrangements, people eligible for Medicaid receive services through private health plans, rather than directly from the state. MCOs may be small, regional plans or large multi-state health insurance issuers. People with IDD typically are among the last eligibility group to be enrolled in managed care arrangements.

Medicaid Managed Care for People with Intellectual and Developmental Disabilities

As of October 2018



Notes:

North Carolina program currently being contracted
Arizona program currently transferring from state to MCOs
Michigan uses local quasi-public entities
Wisconsin uses local, nonprofit MCOs
New York implementing provider-led entities

³ Other managed care arrangements recognized by CMS (and regulated like MCOs) include Prepaid Inpatient Health Plans (PIHPs) and Prepaid Ambulatory Health Plans (PAHPs).

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Medicare

Medicare is a federal health insurance program for older adults and people with disabilities. Unlike Medicaid, it is operated by the federal government without state involvement. People with disabilities become eligible for Medicare through their eligibility for Social Security payments through two primary pathways: Disability Insurance and the Disabled Adult Child program.

- Workers who acquire disabilities and can no longer engage in substantial gainful activity (earning more than minimal income) are eligible for Disability Insurance (DI) payments. After 24 months of DI payments they are eligible for Medicare.
- Adults with disabilities (typically intellectual and developmental disabilities) may also become eligible for Social Security disability payments based on their parents' work record. When the parents of a disabled adult retire, the adult with ID also becomes eligible for cash disability insurance payments and Medicare.

The Medicare program is divided into four parts, each of which provide a different type of health care coverage and require beneficiaries to pay a different deductible, copay, and/or coinsurance (when applicable).

1. Part A: Inpatient hospital stays
2. Part B: Care provided outside an inpatient basis (physician offices, outpatient clinics, etc.) and preventive services
3. Part C: Medicare Advantage (Parts A & B delivered through a private health plan)
4. Part D: Prescription drugs

Dual Eligibility (Medicare and Medicaid)

“Dually eligible beneficiaries” is the general term that describes individuals who are enrolled in both Medicare and Medicaid. Together, the eligibility rules of Medicare and Medicaid create the potential for significant overlap. Individuals with ID are likely to be on Medicaid beginning in childhood or upon turning 18. When their parents retire, they may also become eligible for Medicare through the Disabled Adult Child program.

When an individual is enrolled in Medicare and Medicaid, Medicare serves as the “primary payer.” This means that Medicare pays first and Medicaid covers those items or services not covered by Medicare. Primary and acute care services are covered by Medicare. Home and community-based services are covered by Medicaid. This arrangement creates significant complexity, particularly with lack of coordination between the programs.

In the Affordable Care Act, Congress recognized this problem and created a demonstration to coordinate care and align financing, as well as program administration, for dually eligible beneficiaries. One state – New York – focused their demonstration entirely on people with IDD. States are increasingly requiring Medicaid MCOs to offer aligned “Dual Eligibility Special Needs Plans” (D-SNP) to support increased coordination between the programs for dually eligible beneficiaries.

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Affordable Care Act Coverage and Private Insurance

The Affordable Care Act (ACA) created new regulations and pathways to coverage for individuals and small businesses. Health insurance Marketplaces were created in each state. Plans offered on the Marketplaces are subsidized for individuals, based on income. Health plans for selling subsidized plans in the Marketplace, must adhere to certain requirements. Two significant requirements apply to people with ID.

- **Pre-Existing Condition / Guaranteed Issue:** Before the ACA, people with disabilities were categorically denied access to the private health insurance market, simply on the basis of disability. Now, people with ID applying for coverage cannot be denied on the basis of their diagnosis.
- **Essential Health Benefits:** Exchange plans are required to cover 10 essential health benefits, including habilitation. Habilitation describes services and devices needed to keep, learn, or improve skills, and is primarily used by people with developmental disabilities, including intellectual disability.

Commercial Insurers

Commercial insurance companies offer private insurance to individuals and employee groups. People with ID may have commercial insurance through their parent’s employers or through their own employment. Commercial insurers create networks of providers, authorize services and pay claims, and may impose cost-sharing (copays or co-insurance) when individuals seek care. Members of the plan are likely to face increased cost-sharing if they receive out-of-network services. Individuals with ID may be more likely to seek out-of-network care when they seek services from specialists or providers who are trained or accustomed to serving people with ID.

Commercial insurers are subject to state and federal requirements, including requirements of the ACA if they offer products on the Marketplaces. However, they also have more freedom to set coverage and payment policies than Medicare or Medicaid because program policies are set by state and federal governments, legislatures, and Congress.

Companies that offer commercial insurance frequently also provide Medicaid managed care and Medicare Advantage products.

Conclusion

Despite advancements in disability rights and community living, people with ID continue to face disparities in health care access and outcomes. The first step to addressing these disparities is to understand the key sources of coverage for people with ID. While data on actual coverage rates of people with ID is limited, federal eligibility rules mean that many people with ID are eligible for Medicaid, Medicare, or both. Many more people with ID are also covered by private insurance, either through the Marketplaces or through commercial plans. Each of these coverage sources have a role in improving health care access and outcomes for people with ID.

ⁱ Bershadsky, J., Taub, S., Bradley, V., Engler, J., Moseley, C., Lakin, K. C., Stancliffe, R. J., Larson, S., Ticha, R. & Bailey, C. (2012). Place of residence and preventive health care for developmental disabilities services recipients in twenty states. *Public Health Reports*, 127, 475-485.

ⁱⁱ Ibid.

ⁱⁱⁱ Ibid.

^{iv} Kornblau, B., (2014). The Case for Designating People with Intellectual and Developmental Disabilities as a Medically Underserved Population. Autistic Self-Advocacy Network. http://autisticadvocacy.org/wp-content/uploads/2014/04/MUP_ASAN_PolicyBrief_20140329.pdf

^v National Council on Disability. (2009). The Current State of Health Care for People with Disabilities. <https://ncd.gov/publications/2009/Sept302009>

^{vi} Ibid.

^{vii} Ibid.

^{viii} Ibid.

^{ix} Ibid.

^x Ibid.