

Coordinating Medicaid Services and Supports for Individuals with Intellectual and Developmental Disabilities

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KEY HIGHLIGHTS

- Constraints in the Medicaid fee-for-service system limit access to individualized, high-quality services and supports for individuals with intellectual and/or developmental disabilities (I/DD).
- Medicaid managed care organizations (MCOs) work with individuals and their families to develop person-centered plans that emphasize individual choice, independence, and self-direction.
- State partnerships with MCOs can result in greater independence for the individual, reduction in service gaps, attainment of individual goals, improved health outcomes, and better quality of life.



Contents

Overview	3
Medicaid's Critical Role	4
Managed Care Improves Individuals' Experience	5
Conclusion	11
Endnotes	12

Overview

The delivery of healthcare and supportive services for individuals with intellectual and/or developmental disabilities (I/DD) has undergone significant changes in recent decades.

Individuals with I/DD have multiple chronic conditions.



75% 2 or more chronic conditions

40% 4 or more chronic conditions

These changes are largely attributable to several key factors: the ongoing advocacy efforts of individuals, families and disability rights advocacy groups; passage of the Americans with Disabilities Act (ADA); and litigation, such as the U.S. Supreme Court’s Olmstead decision.^{1,2} These efforts have contributed to a broader set of services and supports that promote informed decision-making, self-determination, and people living and participating independently in their communities. As a result, people with I/DD are experiencing a higher quality of life.³

Despite these positive changes, regulations and resource constraints continue to limit the ability of individuals with I/DD to access individualized, high quality, integrated services and supports. In particular, reliance on Medicaid fee-for-service (FFS) and traditional service models has resulted in a fragmented delivery system where spending and services are not always aligned with measurable outcomes, such as improvements in quality and whole person care.

Individuals with I/DD have a variety of service and support needs, such as:⁴

- Assistance with activities of daily living
- Educational support
- Vocational and employment support
- Social and community integration
- Transportation support
- Assistance accessing healthcare services



Individuals with I/DD may also experience challenges with language, mobility, learning, self-care, and independent living as well as with associated physical or mental health conditions. Individuals with I/DD often have multiple, co-occurring chronic physical health conditions and mental health and substance use disorders (MH/SUD).⁵ A recent survey found that nearly three-quarters of individuals with I/DD have two or more chronic conditions; roughly, 40 percent report four or more chronic conditions.⁶

This calls for an approach that provides and coordinates a comprehensive array of medical care, MH/SUD services, and long-term services and supports (LTSS) across a range of providers. Medicaid managed care organizations (MCOs) can be valuable partners for states as they seek to enhance coordination, improve quality and outcomes, and increase access to home and community-based services (HCBS) to support people using LTSS.

Medicaid Plays a Critical Role

The Medicaid program plays an important role in the lives of individuals with I/DD. It provides coverage for physical healthcare, MH/SUD services, and LTSS, as well as linkages to other services and supports to increase independence and promote meaningful community participation. Overall, Medicaid accounts for more than 75 percent of spending on institutional and community-based services for individuals with I/DD.⁷



Physical healthcare, MH/SUD services, and other social supports are often fragmented and uncoordinated in Medicaid FFS.

States have taken steps to establish comprehensive service systems that support individuals with I/DD. More than two dozen states either require individuals with I/DD to enroll in comprehensive Medicaid managed care plans or offer managed care as a choice for their acute healthcare needs.⁸ Only a handful of states include all healthcare services and supports (i.e., acute care and LTSS) in managed care for individuals with I/DD.⁹

In Medicaid FFS, physical health and MH/SUD are often fragmented and siloed while important resources such as housing, employment supports, educational supports, and nonmedical transportation may go uncoordinated. Among other challenges, individuals with I/DD may not have all of the tools and resources they need to optimize the benefits of self-direction, which can result in poor health outcomes.^{10, 11}

If individuals with I/DD have access to these tools and resources in a coordinated manner, they can live full, integrated, and meaningful lives in their communities. States are increasingly moving towards Medicaid MCOs as a way to address the challenges that many individuals with I/DD experience accessing services in FFS.

Managed Care Improves Individuals' Experience

Managed care programs can be flexible and innovative in benefit design and delivery of services to ensure high quality services are accessible and meet the needs and preferences of individuals. MCOs are also accountable partners to states in achieving desired outcomes.



MCOs deploy flexible and innovative approaches that **address the specific needs and preferences of individuals.**

Individualized Care Coordination and Supports

Successful managed care approaches address the individualized needs and preferences of beneficiaries with I/DD and seek to maximize individuals' independence. For instance, MCOs can increase opportunities for self-direction and informed decision-making. Medicaid MCOs employ a variety of strategies to execute a whole person approach.

Person-centered planning

Person-centered planning is an approach to organizing services and supports with the active engagement and leadership of the individual. Beneficiaries are supported in making decisions that affect their overall health and wellbeing based on their goals, preferences, and choices for how they want to live. Medicaid MCOs play an important role in facilitating this approach.

Anthem's affiliated health plans

Elevating the approach to person-centered care

Plans have worked extensively to incorporate Person Centered Thinking[®] (PCT) throughout their practices. To date, over 1,000 associates have completed a two-day training on PCT, more than a dozen associates have become certified trainers, and selected individuals have become "Trainer-Mentors" who identify new trainers and provide continued guidance.

Among the beneficiaries Anthem serves, 85 percent note high satisfaction with their service coordinator and 88 percent of individuals receiving LTSS feel more comfortable managing their own care since enrolling in Anthem's affiliated plans.¹²



Individuals have meaningful access to self-direction and receive support from MCOs in its execution.

Self-direction

Self-direction empowers individuals with I/DD to choose and manage the services and supports that help them live independently in their own home and communities. Through self-directed approaches, the individual—on their own or with their designated representative—has scheduling and hiring authority as well as control of their budget for personalized services and supports.

Anthem’s affiliated Medicaid plans support beneficiaries who have both budget and employer authority by providing a variety of Financial Management Services models.¹³ When problems arise or if an individual needs additional assistance, service coordinators engage the individual to resolve the issue. Overall, managed care plans work to ensure individuals have meaningful access to self-direction and support them, when needed, in its execution.

Multidisciplinary teams

MCOs form multidisciplinary teams for service coordination, matching team members’ skills and expertise to the needs of the individual and their family (or designated representatives). This whole person approach ensures provision of the right mix of services and supports to meet the unique needs of each individual. For instance, individuals with Down syndrome often experience cardiac and gastrointestinal challenges for which coordination between medical and LTSS can successfully prevent or minimize acute hospitalizations, limit life disruptions, and lead to a better quality of life for the individual.

Medicaid MCOs also align MH/SUD services and supports with physical healthcare as part of this approach. This can include, for example, peer mentoring or peer supports, access to crisis intervention and emergency services 24/7, or even a nurse helpline for non-emergent medical and MH/SUD questions.¹⁴



Individuals receive support from MCOs that **helps them go to work, attend school, and participate in their communities.**

Integration of Supportive Services

MCOs implement a collaborative approach focused on integrated solutions that improve the individual's health, community engagement, and quality of life. This includes facilitating connections to the services and supports that help individuals with I/DD go to work, attend school, and participate in other community activities. MCOs deploy a range of efforts that are integral to community participation and maximizing independence.

Tailored service coordination

MCOs match beneficiaries with a service coordinator who is experienced with and responsible for coordinating individuals' services across multiple programs. The match is based on the experience, knowledge, and skills of the service coordinator and the beneficiary's diagnosis and circumstances, complexity of medical conditions and/or MH/SUD, and intensity of service and support needs. The service coordinator works with the beneficiary and their family to develop a person-centered care plan, continuously assess the effectiveness and responsiveness of the plan to the individual's needs and development, and modify the care plan based on the needs and preferences of the individual and their family.

Anthem's affiliated health plans

Encouraging self-determination and community inclusion

Plans hire service coordinators who incorporate the philosophy of self-determination and the values of self-direction and respect into all aspects of their engagement with individuals with I/DD. These coordinators receive robust training on a variety of topics integral to serving individuals with I/DD, such as person-centered practices, community inclusion and the importance of maintaining community living, and positive behavior supports.

School-based services

MCOs ensure children with I/DD receive necessary services in school and that those services are integrated into their overall medical support plans, as well as their individual education plans (IEPs). MCOs also connect children to services and supports in the community that align with the physical and developmental needs outlined in their IEPs. The services and supports provided through Medicaid MCOs supplement existing resources available to children with I/DD to support their growth and development and prepare them for transition to adulthood.

Employment supports and workforce development

Meaningful employment is an important part of community participation and quality of life for individuals with I/DD. MCOs work in partnership with businesses and supportive employment and vocational/educational programs operated by other state agencies and community-based organizations to improve beneficiaries' access to employment opportunities.

Medicaid MCOs can also support workforce development in the community regardless of health coverage.



MCOs partner with state agencies, employers, and community organizations to **improve employment opportunities.**

Anthem's affiliated health plan in Tennessee

Supporting employment opportunities for youth with I/DD

The plan participates in a unique, business-led employment preparation program called Project SEARCH, where youth with I/DD are employed by the health plan and engage in vocational coursework and training in the workplace.¹⁵

In addition to its role as the host employer, the health plan developed a Business Advisory Council, comprised of local businesses, to advise the program and mentor participants. The health plan accepted into the program and graduated nearly a dozen interns in two years—hiring two graduates as fulltime employees while the others earned positions with employers in the Nashville community—and continues to offer the program to new individuals.¹⁶

Housing services

MCOs connect individuals with I/DD to housing resources including integrated community living opportunities. MCOs and service coordinators work regularly to identify solutions to address barriers to living in the community. Comprehensive MH/SUD supports are a critical piece of wraparound services when needed, in order to help beneficiaries live independently at home and in their communities. Under a managed care program, service coordinators receive training on how to access local housing and other economic assistance programs to support beneficiaries.



Individuals wishing to live independently in the community receive transition supports and additional benefits from the MCO.

Delivery System Enhancements

Medicaid managed care programs may also increase access to home- and community-based options for individuals with I/DD. Medicaid MCOs can partner with states to improve the experience for beneficiaries in several critical ways.

Rebalancing

MCOs work to support states' efforts to shift funding from institutions, such as nursing facilities and intermediate care facilities for individuals with I/DD, to home- and community-based services and supports. During transitions from institutional settings to beneficiaries' homes and communities, MCOs can offer support services—and in some instances additional benefits—to increase the likelihood of successful transitions. For instance, several of Anthem's affiliated health plans offer assistance to beneficiaries with securing accessible housing and needed services as well as service coordination necessary to remain successfully at home.¹⁷

Value-added benefits

Managed care plans offer value-added benefits that can help improve community engagement and quality of life. For individuals with I/DD, this could include non-medical transportation to community locations with programs that support daily living, social integration, and wellbeing. Other types of value-added benefits may include sensory products (e.g., fidget spinners, thinking putty) and healthy lifestyle aids (e.g., digital scale, home blood pressure cuff). These efforts complement the delivery of home- and community-based services and supports and help individuals with I/DD live more independently and participate successfully in their communities.

Anthem's affiliated health plan in Indiana

Helping beneficiaries overcome barriers to care

The plan uses an enhanced benefit to support independence. The health plan provides eligible individuals with \$25 to open up an INvestABLE account as a new enhanced benefit, realizing the \$25 startup cost is a large barrier for some individuals.

These tax-advantaged accounts, which passed as part of the federal Achieving a Better Life Experience (ABLE) Act of 2014, allow individuals with disabilities to save money without the risk of losing their Medicaid eligibility. INvestABLE accounts are federally tax deferred or tax-free if used for qualified disability expenses, such as personal support services, employment training and support, transportation, and housing, among others.



Caregivers have access to a variety of resources through MCOs that **improve the experience of individuals and their families.**

Family and caregiver support

Many individuals with I/DD rely on a significant level of services and supports provided by family members and/or other unpaid caregivers. These natural supports help to ensure individuals can fully participate in their communities, obtain employment, and maximize independence. MCO service coordinators incorporate these natural supports into an individual's service plan, as appropriate, in a way that supplements—not supplants—other covered services and supports.

However, the challenges and barriers individuals with I/DD encounter (e.g., waiting lists, lack of supports in the community) may result in family members serving as the primary, and often only, caregivers. This becomes complicated as the caregiver ages and begins to experience their own health service and support needs. Further, all caregivers need a variety of supports, such as respite, to prevent burnout. Managed care plans can support the needs of caregivers and family members in addition to the individual by working together to ensure the service plan meets the needs of the individual, family, and caregivers.

Anthem's affiliated health plans

Providing resources to support caregivers

Plans offer a variety of resources, beyond respite care, to support caregivers. Examples include access to caregiver support kits, initial assessments that ask what the caregiver needs and what they are capable of providing, as well as help accessing resources in the community (including handling enrollment and paperwork to access additional services and support programs).

Conclusion

Medicaid managed care supports states in building sustainable, high-quality service systems that meet the everyday needs and preferences of individuals and their families.

It also delivers an integrated approach crucial to overcoming the barriers inherent in Medicaid FFS that individuals with I/DD encounter. Medicaid MCOs drive toward a simplified healthcare system that can help improve the health and wellbeing of people with I/DD.

Whole person care coordinated through a Medicaid MCO creates accountability across the system of care and supportive services. Moreover, MCOs work with beneficiaries to develop comprehensive, person-centered care plans that emphasize individual choice, access to the full array of services and supports, independence, and self-direction.

As more states move in the direction of fully integrated managed care for all services and supports for individuals with I/DD, partnering with a Medicaid MCO can result in greater independence for the individual, reduction in service gaps, attainment of individual goals, improved health outcomes, and better quality of life.



MCOs can enhance independence and attainment of goals, reduce service gaps, and improve quality of life.

Endnotes

- ¹ In the landmark Olmstead decision, the Supreme Court found institutionalization to be a form of discrimination under the ADA and required states to provide community alternatives to institutional services to serve people in the most integrated setting possible.
- ² Lind, A. & Archibald, N. (2013, February). Structuring New Service Delivery Models for Individuals with Intellectual and Developmental Disabilities. Center for Health Care Strategies. Retrieved September 9, 2020, from http://www.chcs.org/media/New_Service_Delivery_Models_for IDD_020413.pdf.
- ³ McCarron, M., et al. (2019). Effect of Deinstitutionalization on Quality of Life for Adults with Intellectual Disabilities: A Systematic Review. *BMJ Open* 9: e025735. Retrieved October 5, 2020, from <https://www.nasddds.org/uploads/documents/e025735.full.pdf>.
- ⁴ American Association on Intellectual and Developmental Disabilities. (2019). Frequently Asked Questions on Intellectual Disability. Retrieved March 10, 2020, from <https://www.aidd.org/intellectual-disability/definition/faqs-on-intellectual-disability>. Intellectual disabilities are generally characterized by significant limitations in both intellectual functioning—such as learning, reasoning and problem solving—and in adaptive behavior, which includes social and practical skills. To qualify as an intellectual disability, the disability is usually required to originate before the age of 18. Developmental disabilities are generally more broadly defined to include intellectual disabilities as well as other severe chronic disabilities that can be cognitive, physical, or both. Developmental disabilities manifest during the developmental phase, which is commonly considered to be before the age of 22, and are anticipated to be life-long.
- ⁵ Chapman, S. & Wu, L. (2012, July). Substance Abuse among Individuals with Intellectual Disability. *Res Dev Disabil* 33(4), 1147-1156. Retrieved July 6, 2020, from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3328139/>.
- ⁶ Ervin, D.A., et al. (2014, July 15). Healthcare for Persons with Intellectual and Developmental Disability in the Community. *Frontiers in Public Health* 2(83). Retrieved March 10, 2020, from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4098023/pdf/fpubh-02-00083.pdf>.
- ⁷ The State of the States in Developmental Disabilities Project. (2017). Federal-State I/DD Medicaid Spending Percent of Total I/DD Spending: 2015. The State of the States in Intellectual and Developmental Disabilities, University of Colorado. Retrieved January 1, 2020, from <http://stateofthestates.org/index.php/create-a-chart-2017#chartControls>. Figure reflects federal-state Medicaid spending for all sizes of Intermediate Care Facilities for Intellectual Disabilities, HCBS Waivers, and related Medicaid spending for targeted case management, clinic and rehabilitative services, personal care, and administration.
- ⁸ Gifford, K., et al. (2019, October). A View from the States: Key Medicaid Policy Changes: Results from a 50-State Medicaid Budget Survey for State Fiscal Years 2019 and 2020. The Henry J. Kaiser Family Foundation. Retrieved January 10, 2020, from <https://www.kff.org/medicaid/report/a-view-from-the-states-key-medicaid-policy-changes-results-from-a-50-state-medicaid-budget-survey-for-state-fiscal-years-2019-and-2020/>. Nineteen states enroll individuals with I/DD in managed care on a mandatory basis while 6 states offer managed care on a voluntary basis for this population.
- ⁹ Ibid.
- ¹⁰ Ervin, D.A. & Merrick, J. (2014, September 24). Intellectual and Developmental Disability: Healthcare Financing. *Frontiers in Public Health* 2(160). Retrieved March 11, 2020, from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4173221/pdf/fpubh-02-00160.pdf>.
- ¹¹ Ramlet, M. & Lafferty, C. (2011, June 14). Moving Beyond Fee-For-Service: The Case for Managed Care in Medicaid. American Action Forum. Retrieved January 10, 2020, from http://americanactionforum.org/sites/default/files/AAF-OHC_Managed%20Medicaid_Final_6-14-2011_1_0.pdf.
- ¹² Data from Anthem, Inc. subject matter experts.
- ¹³ Ibid.
- ¹⁴ Program information from Anthem, Inc. subject matter experts.
- ¹⁵ For more information on Project SEARCH, see: <https://www.projectsearch.us/>.
- ¹⁶ Program information from Anthem, Inc. subject matter experts.
- ¹⁷ Ibid.

ABOUT US

Anthem Public Policy Institute

Anthem's Public Policy Institute was established to share data and insights to inform public policy and shape the healthcare programs of the future. The Public Policy Institute strives to be an objective and credible contributor to healthcare innovation and transformation through publication of policy-relevant data analysis, timely research, and insights from Anthem's innovative programs.

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