Addressing the Health Care Needs of People with Intellectual and/or Developmental Disabilities (I/DD)

POLICY BRIEF

February 2026

Key Takeaways

The 10 million-plus Americans with intellectual and/or developmental disabilities (I/DD) have a range of needs, and their care can be complex.

More comprehensive, integrated care and innovative payment models offer promise for improving outcomes and increasing efficiency.

The success of these models is reliant on providers' commitment to listening to and partnering with patients and families.

Care Needs and Costs Among People with I/DD

- As many as 10–16 million Americans have I/DD, which are associated with diagnoses such as autism or Down syndrome. People with I/DD face disproportionate difficulties in accessing high-quality care, resulting in poorer health outcomes, and ultimately shorter lifespans.
- The costs of care for people with I/DD are high. Over 50 percent of people with I/DD have additional medical or behavioral health conditions. A Government Accountability Office study showed that Medicaid payments in 2019 for adult enrollees with I/DD varied across the six states studied, ranging from $51,000 to $70,000 and two to five times as much as care for enrollees with other disabilities. A four-state study found that annual Medicaid payments for hospital and emergency department care were twice as high for children with I/DD as those for the general population.
- Barriers to access likely contribute to these higher costs. Adults with I/DD often experience barriers due to communication difficulties that limit their understanding of health information, as well as other factors such as fear, impaired autonomy, need for accommodations, lack of coordination and continuity, and need for the presence and inclusion of family or support person.

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1. Conditions associated with I/DD are usually present at birth and affect the trajectory of physical, intellectual, and/or emotional development and many affect multiple body parts or systems. For details, go to: https://www.nationalacademies.org/our-work/optimizing-care-systems-for-people-with-intellectual-and-developmental-disabilities-a-workshop.
2. Barth S, Lewis S, Simmons T. Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences: Report to the Medicaid and CHIP Payment and Access Commission. Health Management Associates. October 2020. Available at: https://www.macpac.gov/wp-content/uploads/2021/01/Medicaid-Services-for-People-with-Intellectual-or-Developmental-Disabilities-%E2%80%93-Evolution-of-Addressing-Service-Needs-and-Preferences.pdf.

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Addressing the Needs of People With I/DD in Clinical Care

People with I/DD have sensory and communication needs that can make it difficult to access and participate in care. Families of people with I/DD can feel isolated and misunderstood as they advocate for their family member's needs. Clinicians often receive inadequate training or have limited experience in interacting directly with people with I/DD, leading to challenges in effective communication and high-quality, patient-focused care.

Organizations such as Special Olympics have articulated principles for Inclusive Health, which would address these needs through elements such as accessible physical environments and communications, awareness and training for clinical teams, and intentional inclusion of people with I/DD in care decisions, as well as organization governance.

With support from Special Olympics, Leavitt Partners sought input from stakeholders on the key components of care models consistent with the Inclusive Health principles and key considerations for payment and financing of such models. Input was gathered from individual interviews and a multistakeholder convening, involving people with I/DD and their families, providers, payers, and other experts.

INGREDIENTS OF INCLUSIVE HEALTH

- Sufficient Time with Patients
- Training and Empowerment
- Accommodations
- Partnerships and Team Models
- Inclusive Attitudes
- Other Resources and Supports

Inclusive Health Care Model

Stakeholders said that the ingredients of care models aligned with Inclusive Health include:

- **Time.** Allowing sufficient time for visits to allow for effective preparation and communication.
- **Training and Empowerment.** Ensuring that clinicians and practice staff understand the specific needs of people with I/DD and that everyone can safely handle complex situations.
- **Accommodations.** Adapting physical equipment, technology used as part of the visit, staff practices, or even specific medical treatments.
- **Partnerships and Team Models.** Comprising primary care and specialty clinics as well as coordination with providers of home and community-based services (HCBS).
- **Inclusive Attitudes.** Avoiding stigma or assumptions and actively engaging with the person with I/DD and the individuals who assist them through supported decision-making.
- **Other Resources.** Connecting to services such as transportation and respite care that help people with I/DD and caregivers.

Convening participants also noted several additional recommendations to help providers advance Inclusive Health:

- Have an interdisciplinary team, which may include medical specialists, psychiatry and psychology, dental care, occupational and speech therapy, and other disciplines.
- Avoid diagnostic overshadowing—assuming that new problems are a result of I/DD instead of investigating carefully for other co-occurring causes.
- Guard against overmedication.
- Incorporate communication practices that respect individuals with I/DD and their preferences in shared or supported decision-making, while also welcoming caregivers and understanding their roles and needs.
- Coordinate with HCBS.

Paying for Inclusive Health Care Models

Practices have a range of approaches to treating patients with I/DD, and differ in terms of patient mix with people with I/DD. Some practices treat people with I/DD, as well as a number of other patient populations, while other providers specialize in caring for people with I/DD. When primary care practices serve only a small number of people with I/DD, they can adopt Inclusive Health components, but limited reimbursement often makes it hard to justify the necessary investments. Even practices specializing in I/DD can also find it difficult to achieve sufficient payment to cover needed investments in infrastructure and specialty care.

Different practices across the board report that they have to seek other sources beyond typical fee-for-service reimbursement or may forgo certain investments that could improve their consistency with principles of Inclusive Health.

Common challenges include:

Time-driven coding, without sufficient ability to facilitate flexible, longer visits

Lack of payment for administrative tasks like medical phone calls, prior authorizations, consultation with other clinicians

Complex billing rules for some codes intended to support longer visits (such as chronic care management)

Low payment levels for codes used to bill for services needed by people with I/DD

Lack of payment to make upfront investments for infrastructure and staffing

Lack of support from the practice's parent organization (e.g., the hospital system)

Instead, practices must seek additional sources of funding including:

- Incentive payments for quality results or for contributing to lower costs (e.g., shared savings under accountable care organizations [ACOs])
- Subsidies or zero-interest loans (e.g., from the parent health system)
- Grants and donations
- Medicaid health home payments
- Other designated funds from Medicaid agencies
- Out-of-network payments
- Out-of-pocket payments

For people with I/DD who have the most complex needs, there may be benefit in specialized clinics that focus exclusively on providing comprehensive multi-disciplinary care in a welcoming environment. Kramer Davis Clinic in Nashville, Tennessee was one such clinic – it negotiated with a Medicaid health plan to provide upfront payments to support the comprehensive approach under a risk-based contracting model. However, these specialized clinics may not be accessible to all individuals due to geographic distance, transportation barriers, and limited availability. For this reason, it is important that Inclusive Health-focused options for people with I/DD are available both in traditional medical settings as well as innovative and specialized settings.

Developing Better Payment Approaches for Care for People with I/DD

Based on the input from the multistakeholder discussion as well as a previous environmental scan, the following recommendations identify specific opportunities to change payment approaches to increase opportunities for people with I/DD to obtain care consistent with Inclusive health goals.

- Find better ways to identify people with I/DD diagnoses. Having sufficient data to define the population and understand their history of utilization and needs for both clinical and HBCS is critical to building robust financial models that underlie payment approaches.
- Use a population health approach that considers the range of needs across people with I/DD, similar to approaches for other complex care populations. It is important to adapt the payment approach to the size and complexity of the patients with I/DD seen in a particular clinic.
    - When capitated or risk-based contracts focus on patients with complex I/DD, the definition of "complex I/DD" should be clearly specified in terms of diagnoses, needs, and resource use. This practice can avoid creating incentives to focus on patients with less intensive needs and avoid patients with the greatest complexity.
    - Programs that may serve as models include Wisconsin's Care4Kids program, which provides comprehensive care coordinated on a "medical home" team for youth in foster care, as well as ChenMed's comprehensive physician-led primary care model for medically underserved older adults.
- Establish standards for what constitutes evidence of having an Inclusive Health model and conduct quality reviews to monitor outcomes.
- Encourage providers to a "minimum viable" care model, incorporating elements to provide the basics of Inclusive Health that are possible with limited resources and flexibilities,. With greater resources, practices can innovate and invest in more robust models of care. Options include the following:
    - A broader range of clinical services that are co-located or otherwise easily accessed
    - Flexible lengths of clinical visits.
    - Access to care coordinators and social workers to manage applications for public benefits and address other social drivers of health
    - A range of physical and other accommodations (e.g., a designated sensory room)
    - Referrals to partner HCBS providers
- Partner with payers to pilot models that address payment barriers. Large insurers may be more open to a pilot before considering a broader change in payment. Integration or ties with a risk holder (such as a larger health system or plan) may be critical to success implementation and scaling.
- Engage self-advocates, family members, and caregivers in the processes to design and implement such programs, and require investments on the part of the provider. These efforts should include meaningful decision-making roles and payment for time and expertise.

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