

Health Policy and Systems

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Introduction

Health policy remains largely unresponsive to the health needs and experiences of people with intellectual and developmental disabilities (IDD), and it significantly impacts their access to care and their health outcomes. Financing is addressed in another brief; here, policy and systems recommendations focus on increasing access to care and improving the health status and quality of life of people with IDD.

Recommendations

1. Promote health-data surveillance and other data-collection initiatives.

People with IDD have not been historically well represented in national health-surveillance and population-health data (Office of the Surgeon General et al., 2002). There has been increased awareness of the need for IDD data over the last 20 years; however, there remain significant gaps in the ability to define, and effectively track race, ethnicity and other demographics, health status, and healthcare utilization of people with IDD (Krahn, Haverkamp, & Bonardi, 2024). While notable healthcare-delivery systems have been developed with and for people with IDD over the last 2 decades (Ervin, 2025), there have been no coordinated or policy-driven efforts to collect and analyze impact, efficacy, or other data that could be used to understand how people with IDD use and experience healthcare. The collection of data with markers for an IDD diagnosis should be required by publicly funded insurance programs, and healthcare providers should be incentivized to share data and perform relevant analyses.

2. Develop quality measures to prioritize health outcomes.

There is no consistently applied framework to address either health across the lifespan or health

Plain Language Summary

People with intellectual and developmental disabilities (IDD) often have trouble getting the healthcare they need. Here's what needs to change to make healthcare better for them:

Get Better Information

Right now, we don't have enough information about the health of people with IDD. We need doctors and insurance companies to collect more information about their health needs and the care they receive. This will help us understand how to take better care of them.

Set Goals for Better Care

We need to create clear goals for what good healthcare looks like for people with IDD. We should ask people with IDD, doctors, and others who help them what these goals should be. Doctors should also get special training to learn how to take better care of people with IDD.

Make Technology More Available and Accessible

New tools like video doctor visits can help people with IDD get better care. But not everyone has access to these tools. We need to make sure everyone can use them and that they work well for people with different needs.

Make Systems Work Better

Many people with IDD use Medicaid insurance. Right now, if they move to a different state, they lose their insurance and have to apply for it again. This is very hard for them. We also need to make sure that all the different people who help them—like doctors, insurance companies, policymakers, and others—work together better.

All these changes would help people with IDD live healthier lives and get the care they need more easily.

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Priorities for people with IDD (Pham et al., 2024). Development of such a framework must include people with IDD, and it should also engage healthcare providers, insurers and managed-care providers, and health advocates. The Canadian Consensus Guidelines (Sullivan et al., 2018), in which clinicians worked with researchers and health advocates, including people with IDD, to arrive at a clear set of clinical guidelines and ways to communicate about health care, provide a potential model for such a framework in the United States. Healthcare professionals and systems should be incentivized to provide care to people with IDD through the formal designation of these individuals as members of a medically underserved population, which could increase rates paid for their care.

3. Advance and make accessible health technologies available.

Health technologies hold the promise of improving safety, healthcare delivery, and health outcomes for people with IDD. These technologies can increase access to primary and specialty care and can detect risks and guide individuals toward appropriate care more efficiently (Stanford Medicine, 2018). The implementation of health technologies varies greatly across states, and no standardized measures exist for assessing their quality and accessibility. While the use of telehealth expanded during the pandemic—due in part to temporary Medicare and Medicaid reimbursement policy changes, other potentially more effective technologies remain underutilized due to the lack of clear, sustainable financing mechanisms (Friedman, 2023). Policies must ensure reliable and affordable internet access, effective accommodations of the needs of those with communication or sensory impairments, and sustainable funding models for promising health support technologies. Universal accessibility standards, in addition to those for patient privacy and cyber security, need to be enforced to ensure optimal accessibility to appropriate prevention, risk identification and mitigation, and intervention strategies that lead to optimal health outcomes.

4. Explore and develop options for Medicaid portability and integrate systems of care.

Medicaid is a state-operated program and is not portable across state lines. Medicaid beneficiaries in one state who move to another state lose the crucial insurance coverage of their prior state while they attempt to establish Medicaid eligibility in their new one. About 1.2 million adults with IDD rely on Home and Community Based Services (HCBS) and other long-term supports financed under Medicaid waiver and state-plan services and may be significantly impacted if they move to a state with a waiting list for eligibility for Medicaid-funded HCBS. Children with IDD receive supports through special education and pediatric systems of long-term care. These systems are not coordinated, and policies must ensure that systems coordination, Medicaid portability across jurisdictions, person-centered and self-determined services, measurable outcomes, and standards to which professionals can be held accountable are established. Demonstration pilots, models, and other innovations that disparately impact people with IDD should be reviewed for efficacy, impact, and scalability.

Conclusion

National policies should prioritize data collection and surveillance initiatives, establish uniform quality measures for improved health practices and outcomes, continue to build clinical capacity for comprehensive health service delivery, promote ongoing advances in health technologies, and promote mechanisms to integrate systems and remove barriers to improving the health and well-being of people with IDD.

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